

Multiple Sclerosis Waikato

Issue 78 – August 2023

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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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IT Wizard

ake Waas is not a gamer... nor is he a social media zealot, but he is very passionate about computers – computer programming to be more accurate and he is becoming recognised as someone who knows his stuff in the computer world.

Jake is the proud owner of a Relapsing/Remitting MS diagnosis which he received in 2012 aged 25.

"With my diagnosis I was given a lot of literature about the disease and sort of left to deal with it. I struggled through the next five years believing this was my new normal and was a bit of a wreck until my neurologist suggested trying Natalizumab (Tysabri). It basically changed my life. "I wasn't tired anymore and found that I could now think clearly."

Jake was doing a Bachelor of Science, majoring in Physics, at the University of Waikato at the time. "It was an enjoyable experience – the lecturers then were an all-star cast of mathematicians and physicists – I was lucky to have them." Jake says they were understanding of his quirkiness and believed just because someone didn't fit the norm didn't mean that they weren't deserving of good grades.

While at University Jake made good use of the library's collection of computer literature. He devoured books written by computer gurus in the 1980's. This was a time before graphical user interface (icons) that came in with MacIntosh (1984) and Windows (1985). Jake cites Conrad Barski's book 'Land of Lisp' (which he found on line) as a big influence. Lisp (**LISt P**rocessor) is the second oldest programming language still in use – dating back to the 60's).



Jake Waas

"I wasn't that fussed on the style of computer language being used at Waikato University, so I taught myself computer programming."

"I am an old - fashioned style programmer - and use the programme language LISP - popular in the '80's. There were a lot of good ideas developed in the 80's that are still relevant today" Jake does a Phlog (not a weblog but a goPHerlog...) on which he writes about programming "sharing old fashioned wisdom" and teaching rare programming techniques. He also does a podcast - 'The Lispy Gopher Show' which is recorded on Wednesday's (NZ time) to arrive in the USA (where most of his followers are) on Tuesdays. The podcast has been going for about a year and he calls it a 'labour of love'. Jake points

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out "I'm not a computer professional – in fact I am wary of anyone going by that name. I believe if you are getting paid to do something – it's a job not your passion." Jake's 'handle' for his podcast is 'Screwtape'. "He's a bit of a dodgy character in the C.S. Lewis book 'The Screwtape Letters'". So, is Jake dodgy? "Well, you have to have a bit of a 'hacker' culture about you. You don't learn this stuff in the normal education system"

It was through those mediums that Jake got noticed by Christine Webber who is head of a charitable organisation called The Spritely Institute. This group helps 'friends' connect directly with each other without going through commercial outlets such as 'Facebook' or 'Twitter'. They operate on a system called SDF. org, this is a charity in the USA which provides 'public access' services for free. "They have a community which operates a bit like a radio station. - "They told me my podcast was very 'experimental' which I take as a compliment - I hope."

Christine invited Jake to attend a week long on-line festival called '2023 Spring Lisp Game Jam' where participants took part in developing games and sharing ideas. Over the week each participant, or group, designed a game which the others got to try out and rate. About 30 games (including Jake's) reached the completed stage. "I'm not really a gamer so my game as such wasn't among the favourites but they did love the programme (LISP) that I was using.

For Jake, his highlight to date has been receiving some quirky feedback from a listener called Kent Pitman. "This guy is a major 'LISP' celebrity and would be among the top 20 computer specialists in the USA. To have him listening in...and commenting favourably – that's pretty cool!"

Ian Maxwell



I would like to introduce myself. My name is Kate, I am the Research Nurse/Coordinator for Neurology Clinical Trials and collaborative research projects, at Waikato Hospital.

MSBase is an international registry dedicated to evaluating outcomes data in multiple sclerosis and other neuroimmunological diseases.

The purpose of the MSBase Registry collection is to conduct analyses that link patient characteristics and treatment with specific outcomes such as disease severity. The results are presented at international conferences and published in scientific journals. We hope that the research will improve outcomes for people with Multiple Sclerosis by changing clinical practice.

Locally data can be used to support patient care and nationally data can be pooled from regions across New Zealand to guide current and future care and support for patients with multiple sclerosis.

As you may be aware the Waikato's participation in the MSBase project began in 2018 and was led by Dr Jan Schepel. Dr Schepel has left Waikato Hospital to return to Europe. The project is now headed by Dr Beatriz Romero Ferrando.

In order to uphold research standards and provide quality data to this project we are updating the MSBase participants' consent forms. We are also contacting new potential participants about the project.

For additional information about the MSBase Registry and The



MSBase Foundation which is the not-for-profit charitable organisation managing MSBase internationally, go to https://msbase.org/

The Waikato Hospital Neurology Department is grateful for the support we have received for this project from of Multiple Sclerosis New Zealand, the New Zealand Multiple Sclerosis Research Trust and Multiple Sclerosis Waikato.

If you have not been contacted about consenting or reconsenting to this research project or would like to find out more about it, please contact us:

Kate Ives, Research Nurse/ Coordinator Neurology Department, Waikato Hospital, Phone 021 549 791

Tania Bull, Clinic Nurse, Neurology Department, Waikato Hospital,

Phone: 021 914 058 Email: neuroresearch@ waikatodhb.health.nz

Liz Hogan, MS Waikato Phone 07 8344741 Email liz@mswaikato.org.nz

Karen Bird, MS Waikato Phone 07 8344742 Email karen@mswaikato.org.nz



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Strangest MS symptoms from head to toe

Extreme fatigue, clumsiness, weird prickly sensations, sluggish thinking, wonky vision -these are classic and common first symptoms of multiple sclerosis, or MS. But the expected stops here. Damage to the central nervous system, aka your brain and spinal cord, is what causes these symptoms. That's a wide range of functions that affect many different people. So it can show up in some strange and varied ways.

Trapped in a Bear Hug

It's not a warm and cozy kind of hug. Called banding, this MS symptom feels like something's squeezing you firmly about the chest and won't let go. It can strike anywhere between your waist and neck, or just on one side. You might have pain or breathlessness. It happens when damage from the disease blocks or garbles the messages from your nerves. Spasms in the muscles between your ribs trigger the tightness. It often passes on its own.

Out-of-Control Laughing or Sobbing

Pseudobulbar affect, also called PBA or emotional incontinence, prompts random outbursts of tears or laughter that have nothing to do with how you feel. Nerve damage in the part of your brain that controls emotions can cause your responses to get all mixed up. You might worry about it happening when you're in public, or in a serious setting. Antidepressants can help.



An Itch You Can't Scratch

It's the itch that isn't. A sudden, intense tingle crops up out of the blue, anywhere on your body. But there's

no skin irritation or allergy to scratch or apply rash cream to. This kind of itch doesn't stem from your skin. Dysesthetic itching is a nerve-related sensation that passes quickly. It's treatable with meds for epilepsy. Carbamazepine, gabapentin, pregabalin and phenytoin are a few.

Shocking Face Flashes

Nerve damage can trigger trigeminal neuralgia, a burning, stabbing, or shock-like pain in your cheek or jaw. It might fade fast or linger for a few minutes. Though rare, it can be a first symptom of MS. You might feel it come on as a tingle, numbness, or ache on one side of your face, like dental pain. Anticonvulsant meds such as carbamazepine, lamotrigine, or sodium valproate can help.

Fiery Feet

Dysesthesia is an unpleasant "altered" sensation like burning, prickly pins-andneedles, numbness, and creepy-crawlies in any part of your body.



For example, your feet might suddenly feel scalded, with no heat source -- or damage -- at all. Your brain gets distorted nerve signals, so it struggles to relate to something it recalls or imagines. Sometimes it comes up with some pretty crazy stuff. You can treat the weird feelings with nerve pain meds.

Hard to Swallow

Swallowing isn't as simple as it seems. The nerves and muscles in your mouth and throat must work with your brain. With MS, the muscles you need to do it can weaken. Mixed-up nerve signals and sensory distortions can make it hard to chew or control the food or liquid in your mouth. Or you might feel there's something stuck in your throat when there isn't. It usually happens at a later stage of MS, but it can show up earlier, too.

Spine-Tingling Shock

Lhermitte's sign is really a symptom. It's a sudden "electric" zap that shoots down your spine and legs. It happens usually when you flex your neck forward, as when you get your hair trimmed. (Another name for it is the barber chair sign.) Lesions in the cervical spine -- your neck area -- cause it. Lhermitte's goes away as quickly as it comes, so it typically doesn't need treatment.

Blurred Vision

Damage to the optic nerve (optic neuritis), which links your eye to your brain, can trigger something called Uhthoff's phenomenon. This means your vision briefly goes blurry when your body temp rises. (Your other MS symptoms may get worse, too.) Exercise, hot baths, warm weather -- even hair dryers -- can all make eye-to-brain signals iffier than usual. It can help to take a cool shower, use a gel pack, and drink lots of cold water before you exercise or go out in the heat.

Optical Illusions

Another optical trick MS can play is the Pulfrich phenomenon. Optic neuritis triggers this one too. It's a 3-D illusion caused by a conflict in your vision. Let's say an object is headed toward you

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Strangest MS symptoms Continued from page 3

in a straight line. Instead, you might see its path as an elliptical orbit. An oncoming car might appear to swerve toward you, or you'll miss a ball as you try to catch it. A special filter in front of one eye can help balance your vision.

Sudden Spasms

Abrupt, brief spasms called paroxysms happen when electrical discharges fire in damaged areas of your brain. They might surge through your arm or leg, or the muscles you use to eat and speak. Although they can repeat several to many times a day, the bout usually ends within a few months. While scary, they're not the same as seizures. You can treat them with muscle relaxants like baclofen or orphenadrine.

Migraines

Migraines are sudden headaches that can last from several hours to days. They can sometimes be the first MS symptom. People with MS are twice as likely to have them. They can bring on nausea or make you sensitive to sound and light. This can keep you from your regular activities. People with MS seem to have family histories of migraine, so researchers are looking for a link.



Hearing Problems

What's that you say? Rarely, hearing problems can be a first symptom of MS. It might have a link to swelling and scar tissue near your auditory nerve, which carries

info to your brain. Plaque buildup on the nerves along this pathway can lead to it, too. These episodes usually improve, and permanent deafness is rare.

Vertigo

If you have vertigo, you may feel like you -- or the area around you -- is spinning. It can throw off your balance way more than just dizziness. You might also feel lightheaded or queasy from the sense of motion. It happens to about 1 in 5 people with MS. It can stem from damage in the same pathways that control your hearing and vision. Treatment can include physiotherapy, which studies how your movements affect it.

If you are suffering with any of these symptoms, please do reach out and talk to Liz or Karen. Treatment options are growing all the time and there may be something that can help alleviate these symptoms for the day to day.

This article has been adapted by Belinda Butterfield RN, MS & Parkinsons Society, West Coast, from the medically reviewed Web MD article by Melinda Ratini, DO, MS on March 07, 2021

MS Waikato turns 60

MS Waikato has now been providing support services in the region for 60 years. We were established in August 1963, and known at the time as the Waikato Multiple Sclerosis Society.

The late Alma Neeve (JP) was the visionary who saw the need for an organisation to be formed. She initiated and carried out the preliminary action leading to a public meeting, which led to the founding of the then Society. Mrs Neave continued her service to people affected by MS until 1977 when ill health forced her to retire.

Over the years, the organisation has grown, providing support services to those impacted by other neurological conditions, in particular Huntington's Disease.

In 2001, we became a registered Charitable Trust – MS Waikato Trust.

This newsletter, we believe is the 284th edition since our inception. Over the years the look of our newsletter has changed considerably, we have shared a couple of titles used below – originally printed in black and white this was produced with a carnation on the corner, a red carnation was historically used to symbolise MS.



In 2007, we launched our first colour newsletter and held a competition amongst members to name it. Dr Brian Mahood won this, suggesting ManuScript from the Latin word manuscriptum, and tying this in with our logo.



While we operate independently, we are affiliated with the MS Society of New Zealand. In 2010, our colours for MS were changed by MSNZ to orange, with the logo's and colour scheme we now use today.

We are currently providing support services to 330 clients and many families/whanau and carers who we also support throughout the greater Waikato and Coromandel regions.

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Farewell to Richard

We have bid a fond farewell to Richard one of our wonderful exercise assistants after he was offered a great work opportunity with Riverside Adventures Waikato.

Since 2016. Richard had been helping Margaret each week with our gym classes. In running the classes all the exercises have to be developed to suit an individual's condition and disability, so all attendees are following a programme tailored to their needs. Richard got to know many of our clients as he supported them with their programmes. If Margaret has been on holiday, he has happily stepped in and led the class. We would like to extend our

thanks and appreciation to Richard for the incredible support and to wish him all the very best.

Sue, another of our wonderful volunteers continues to assist Margaret. The exercise classes are held twice weekly, on a Monday and Wednesday morning at Anytime Fitness, Clarence St, Hamilton. If you have not been before and are interested in trying the classes, please speak to Liz or Karen who will arrange a visit for you. The classes are supported by MS Waikato to ensure that they are affordable for everyone, we just ask that all attendees have paid their subs and make a contribution of \$2 per session.



Richard and Margaret



KAKEPUPU 10 Challenge Climbing for Motor Neurone Disease and Huntington's Disease

On the 18th November, our HD Neurology Nurse Ruth Mylechreest will challenge herself to walk Mt Kakepuku 10 times in 24 hours to raise funds for Huntington's Disease and Motor Neurone Disease. This will be an incredible 75km, 4,490 metres in elevation.

To make a donation, scan the QR code below, or go to the link below - https://givealittle.co.nz/ fundraiser/nurse-climbing-75kmfor-mnd-and-hd you may wish to join Ruth on the day and walk part of this too. Ruth is a Neurology Nurse and is challenging herself to climb Kakepuku Mountain 10 times in 24 hours. This is approximately 75km, 4490 metres in elevation, to raise funds and awareness for Motor Neurone Disease and Huntington's Disease.



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Huntington's Disease and Nutrition

Getting proper nutrition is especially important for people with Huntington's Disease. Studies have found that Huntington's patients are often underweight for their height, and require more calories than usual per day. This is because their constant movements and metabolic changes lead to higher energy needs. Specialized diet changes will ensure that patients receive enough calories through balanced diets and are able to overcome eating limitations.

Food suggestions

People with a known risk of developing Huntington's — such as those with a family history of the disease — may decide to begin consuming certain types of foods documented to be good for the brain. These so-called "brain foods" include vitamin B12, foods rich in antioxidants and omega-3, and healthy fats, which are found in foods such as nuts, olive oil and avocados. Research has also suggested that a lower intake of dairy products may help delay onset of the disease.

Huntington's patients should aim for a body-mass index (BMI) at the higher end of the healthy range, or a BMI of 24 to 26. Milk, yogurt, cream, cheese, beans, meat and fish are calorie-dense foods that can help achieve that. Sweeteners like chocolate, sugar, honey and syrup can be mixed into drinks and desserts for an added energy boost.

Swallowing difficulties and Huntington's disease

People with Huntington's may have trouble swallowing food, and can choke on food easily. Several measures can be taken to prevent this. Increasing proportions of soft food such as mashed potatoes, or adding gravy, can help ease

Nymbl Improve your balance and cognitive function.

Improve your balance at home, Nymbl is a free personalized app for your unique balance needs.

Research shows that falls happen when we are distracted, not when we are focused on our balance. Nymbl helps prepare you for these real-life experiences and distractions by giving you a simple balance exercise to do at the same time as you play a fun brain game on your device.

Challenging your brain and body to work together is what helps improve your balance reflex. Nymbl's scientifically proven app can improve balance by 30%!

Whether you're seated or standing, Nymbl adapts to your unique balance needs - while having fun! All you need to use Nymbl is a phone or tablet. If you don't have a phone or tablet, enrol in Nymbl (with your email address) and gain access to the weekly educational email program.

Download the app to your device by searching "Nymbl Training" in the Apple App Store or Google Play Store, or go to https://fallsfree.co.nz/ for more information. swallowing. Difficult foods to swallow such as flaky puff pastry, raw vegetables, apples, pears and highfiber white bread should be avoided. Eating small but frequent amounts of high-calorie, nutrient-dense foods such as avocados, smooth nut butters and hearty soups can prevent choking while ensuring adequate calorie intake.

Speech therapists are able to provide regular assessment and advice, it may be beneficial to see one before any problems begin.

Tools for meal preparation and consumption

Kitchen tools such as a food processor and blender can help make food easier to swallow. Utensils that are easy to hold, larger plates, cups with lids to prevent spillage, and dishes to keep food warm for longer durations all will help Huntington's patients enjoy their meals.

Tube-feeding in Huntington's disease

People with advanced Huntington's may no longer be able to feed themselves or safely take food by mouth. In these cases, tube-feeding, also known as enteral feeding, may be necessary. Tubes can be inserted either through the nose to the stomach (naso-gastric), or directly to the stomach (percutaneuos endoscopic gastrostomy) or small intestine (jejunostomy). Surgery is required to place tubes directly into the stomach or intestine.

The attending physician will usually suggest the option to begin tubefeeding, which can be done at home by the patient or with help from a caregiver. The site of tube insertion should be kept clean and dry. Special liquid food containing carbohydrates, protein, fats, minerals and vitamins can be given through the tube.

https://huntingtonsdiseasenews. com/huntingtons-disease-andnutrition/

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Alinkers

MS Waikato has an Alinker which is for client use. If you are interested in trialling this for about 6 weeks please contact Liz for further information.

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.

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.

Dogs in Homes

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

MS Awareness Week MS Awareness week - 11th to the 17th September. This is a national awareness week to raise public

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awareness and understanding of MS. We are looking for volunteers to assist with our stalls at Chartwell Shopping Centre on 13th and 14th September or perhaps you may like to organise a fundraiser or stall yourself. We would love to hear from you, if you are able to help, please phone Janet

on 8344740 or email janet@mswaikato.org.nz.

TravelScoot

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

Library Books

Please remember we maintain a library of books. With books to support MS and HD, a list of titles is available on our website www.mswaikato.org.nz. Please contact us if you would like to borrow a book.

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.

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

WHANGAMATA RSA QUIZ

Saturday 30th September – 7pm

Come and join the quiz night at Whangamata and be in to win a prize. Tickets are \$25 each, create a team of 6. Light supper provided and there will be a silent auction. To book a table for your team, ring Karyn 022 643 2515 All proceeds to MS Waikato

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





Hamilton City Council







grassroots

WDFF 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

September 2023								
SUN	MON	TUE	WED	THU	FRI	SAT		
					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 to be advised 10.30am	8	9 MS Walking Group 9am The Veranda Cafe Hamilton Lake		
10	MS Exercise Class 10.30am - 11.30am MS Awareness Week	12 MS Awareness Week	13 MS Exercise Class 10.30am - 11.30am MS Awareness Week	14 MS Awareness Week	15 MS Awareness Week	16 MS Walking Group 9am, The Veranda Cafe, Hamilton Lake MS Awareness Week		
17 MS Awareness Week	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	21	22	23 MS Walking Group 9am The Veranda Cafe Hamilton Lake		
24	25 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	26	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	28 MS Support Group Mometewa Matamata 10.30am	29	30 MS Walking Group 9am The Veranda Cafe Hamilton Lake		
October 2023								
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November 2023

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

MS Waikato Trust, 20 Palmerston Street, PO Box 146, Hamilton 3240 Tel 07 834 4740, Email mswaikato@mswaikato.org.nz, Website www.mswaikato.org.nz Disclaimer: "MS Waikato accepts no responsibility for accuracy of information contained within this newsletter."