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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the 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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ManuScript is brought to you by:



Community Angel



Lisa enjoying sorting Kaivololution at The Serve.



Lisa, perhaps not enjoying the studying as much.

Many of us see people around us in need of help and think 'I probably should do something'. And yet for various reasons we park that thought in the back of our minds and carry on with our lives. But Lisa Rayner-Strong sees and acts – and manages to do lots of other things as well as living with MS.

Lisa received her first tentative diagnosis of MS in 2010 – just after the birth of her first child and two months before her wedding. Her initial symptoms were 'fuzzy' eye and weak legs. She was a little scared at the diagnosis as she knew nothing about the disease and there wasn't a lot of information about. Lisa was put under the care of the neurological department at Waikato Hospital and initially put on a programme of steroid treatment for her eyes. This worked well but after moving to Auckland for her husband's work she struggled to get the same support and her condition deteriorated to affect both eyes and twitchy hands.

Now back in Hamilton Lisa is under the care of Neurologist Jan Schepel

and nurse Karen Clark. "They have been amazing support. Lisa has been on the drug natalizumab (an infusion every six weeks) for three years which has removed any problems with her eyes. But the fatigue side of things is still an issue. "There is no remedy for fatigue – you just have to get on with life and work your way through it". Lisa has been determined not to let MS be a cage and has got out and volunteered at her girls' (now three of them – aged 6, 8 and 10) kindies and school.

Lisa has always been a person to offer help where needed and when she became increasingly aware that there were people in the community struggling to feed themselves and their families she started making food parcels and delivering them to the needy. "Food is a massive need for people and it is the most basic way you can help someone".

While out in the community Lisa had become aware of a group called 'Serve Trust' who were helping not just the homeless but anyone struggling to make ends meet.

Community Angel cont...

“They are not affiliated to any organisation (political/religious) but are a group of volunteers who provide a safe place for clients to come for help”. When, in 2017, they shifted their base to the old Hamilton Workingmen’s Club building in Harwood St Lisa got in contact and offered her services. She is now one of nine meal service co-ordinators and is rostered on two days a week. She also helps out with the cooking and works on Saturday liaising with community group Kaivolution for food donations. “We don’t just provide our clients (who fluctuate from 30-100) with food – we can offer them bathroom packs and items like blankets”.

Lisa is currently in her second year of a four year Bachelor of Social Work at Massey University. She spends about 40 hours a week doing on-line study and spends one week each semester on Campus in Palmerston North. It works out really well as the degree requires you to do 50 hours voluntary work - so ‘Serve’ covers that nicely.

In her spare time Lisa and hubby upcycle stuff they pick up from second hand stores. A special interest is doing up guitars and selling them on. “We are a musical family. We all play instruments and have family ‘jam’ sessions with friends on Wednesday nights – it’s a good way to catch up with each other and chill a bit”.

And ... if that’s not enough she has another passion on the back burner. Lisa is really interested in NZ History especially the New Zealand Wars. Don’t get her started on the injustices dealt out to Maori and questions like “Why is Hamilton named after a dude who never even came here...?” If you ever find yourself opposite Lisa at a function – prepare yourself for an interesting encounter – I for one have been dutifully informed!

Ian Maxwell

Scholarships, Grants and Awards

The MS Society of New Zealand has a number of scholarships available which may be of interest to you.

- **Round 1:** 1 April – 30 June 2019
- **Round 2:** 1 September – 31st October 2019

Mastering Mountains Grant

A grant created by the Mastering Mountains Charitable Trust and MSNZ with the aim of:

‘assisting people who have been diagnosed as having Multiple Sclerosis, to overcome a specific obstacle so that they can achieve a specific outdoor pursuit’.

Application Deadline:

- 1 September – 31st October annually (Mastering Mountains Grant – NZ based challenges)

Mastering Mountains Expedition Grant

The Mastering Mountains Expedition Grant aims to assist people who have been diagnosed as having MS to participate in an overseas outdoor expedition or adventure with World Expeditions.

Application Deadline:

- 1 April – 31 May annually (Mastering Mountains Expedition Grant – Overseas challenges with World Expeditions)

Dorothy L Newman Scholarship

The Dorothy L Newman Scholarship assists people who have been diagnosed as having MS and as a result are unable to continue in their present employment, who need to change their employment and undergo a course of retraining in order to do so.

Application Deadlines: There are two funding rounds open each year

Esme Tombleson Awards

Esme Tombleson was the co-founder of the Multiple Sclerosis Society of New Zealand in 1961 and from 1975 was President for many years.

In honour of her work, the MS Society of NZ offers the Esme Tombleson Award annually to people in New Zealand for the ‘Person with MS of the Year’ and ‘Caregiver of the Year’.

Application Deadline: 30th September annually

Outward Bound – Aspire Scholarships

9th – 16th September 2019

Aspire is a low impact discovery course which is suitable for people ages 27+ with a mild physical impairment. Participants will experience activities like sailing, rock climbing, kayaking and high ropes, but Aspire is designed to exclude high impact activities such as running or carrying a heavy tramping pack.

Successful scholarship applicants will receive 80% funding towards their Aspire course fee. That means that you only pay \$500 towards this experience of a lifetime.

To apply visit the **Outward Bound website**

For more information and details about these scholarships and grants please visit the MS Society of New Zealand website, <https://www.msnz.org.nz/scholarships-and-grants/>.

HD Family Day Out 2019

Our HD families had a fantastic day out at Totara Springs last month for our second HD Family Day. The weather was stunning, which helped to bring a good vibe to the day, and people mixed and mingled making valuable connections and sparking friendships. Our people enjoyed and participated in many different activities, from Top Town games, The Flying Kiwi, Mini Golf, Slug Guns, The Rock Wall, and Archery; there were plenty of laughs and friendly competition.

The day came to a relaxing close with a swim in the heated pool. From two to 82 years old, and all ages in between, our families had a lot of fun! Some commented that the day was like “a big family get together”. The photos below capture the day well.

A big thank you to the Cambridge Lions Club for funding the event, also to Waitomo Fuels and Daniel from HDYONZ for their support too.



The Michael Ford Memorial Charity Golf Tournament

Our annual golf tournament took place on Friday 5th April. The event is one of our major fundraisers and is now in its 20th year.

The tournament was held at Ngahinepouri golf club, it is a beautiful country course, we were made very welcome and had a great response to the change of venue.

It was a fantastic day with perfect weather, for which we had a full field and quite a few new faces on the course too. The event raised a total of \$8,200.

Overall best Stableford was awarded to Chris Bickham, with Joanne Ford joining us to assist with the prizegiving ceremony.

Thank you to our generous sponsors and to the players without which the tournament would not be possible. In particular, we would like to thank the Ngahinepouri golf club who donated the course to us for the day. Thank you also to our wonderful volunteers – Sue, Jeremy and Helen who gave up their time to assist on the day.

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 and education services for our clients and their families.

Please do remember our sponsors and support them too.

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MS in the Fall and Winter: 5 Ways to Stay Well

After the hot, humid days of summer, the colder temperatures in the fall and winter can come as a shock to our bodies. If you have a condition like multiple sclerosis (MS), cold temps can make your symptoms worse and make you flat-out uncomfortable. You might find that it's harder to move your limbs, you get more muscle spasms than normal, or your muscles feel tighter.

Doctors aren't sure why cold temperatures make MS symptoms worse. But they think that the condition can alter the way you feel temperature changes.

If your symptoms get worse in cold weather, it's usually for short time. A few simple tips can help you stay comfortable and warm in the fall and winter.

Try to get moving. When you have MS, there may be times when you find you can't move around as easily as you'd like. When you can, try to get some moderate physical activity like walking or stretching. It'll help you burn energy and warm up.

Dress in layers. This will help keep you warm. And if you get too hot, you can easily remove layers and stay comfortable. When it's very cold, it's a good idea to wear hats, thick socks, or lined boots. This will keep heat from escaping through your head or feet.

Keep your hands and feet warm. Doctors believe that MS can cause blood vessels in your hands and feet to overreact to cold temperatures. If you have MS, you may also be at risk for Raynaud's phenomenon, a condition in which your fingers and toes lose heat. They turn from white to blue to red as the blood begins flowing again. You may feel numbness, pain, or like someone is sticking you with pins and needles.

To protect your hands and feet from the effects of the cold, try wearing hand warmers or using a heating pad. But don't place the heating pad directly on your skin. It could cause burns or blisters.

Warm your insides. The easiest way to do this is to eat hot meals like soup. You can also sip hot drinks like tea or coffee. Pour them into an insulated mug to keep them warm longer and help limit your trips to the kitchen.

Get some sunshine. Even on crisp fall and cold winter days, who doesn't love the feeling of sunshine on their shoulders? Step outside and soak up some rays. You'll warm up, and you'll help your body make some much-needed vitamin D. An added benefit? A little sunshine might help boost your mood.

Source: <https://www.webmd.com/multiple-sclerosis/ms-fall-winter>

AGM Updates

The MS Waikato AGM was held on the 21 March, at this time Leanne Milligan retired from the board. 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 have given and the knowledge they have shared.

We are fortunate to have a strong and robust board, Marsha Marshall will continue with the role of Chairperson, our other Trustees are Mark Etheridge, Mike Tuck, Graham Derrick, Desley Clarke, Keith Small and William Hughes.

ME/CFS and Fibromyalgia

MS Waikato also provides support services for people affected by ME/CFS and Fibromyalgia. We employ a qualified Field Worker and our services include the provision of information and education, advocacy and monthly support groups.

The ME/CFS and Fibromyalgia group have their own quarterly newsletter, Koru, which is written specifically to provide information and support to this client group.

If you would like to receive an electronic copy of this please notify Tracey by emailing tracey@mswaikato.org.nz.

Continued progress, but also caution, in the fight against Huntington's disease

CHDI Foundation's 14th Annual Huntington's Disease Therapeutics Conference held in February 2019 shares some key developments in the search for the first HD treatments.

On January 28, pharma giant Roche announced that it had enrolled the first participant in GENERATION HD1, its historic global Phase 3 clinical trial of a gene-silencing drug that, if successful, could slow, halt, and perhaps even reverse HD symptoms. In the coming months, Roche aims to enrol a total of 660 clinical trial volunteers in 15 countries. They will receive either the drug (called RG6042) or a placebo in monthly spinal taps over 25 months.

The start of the trial comes less than a year after the presentation of the impressive Phase 1 trial results at last year's Therapeutics Conference. RG6042 significantly reduced the levels of the mutant huntingtin protein in the cerebrospinal fluid of the clinical trial volunteers. Because of those results, Roche took the unusual step of skipping a Phase 2 trial and going directly to Phase 3.

Exciting announcements about other trials

On January 22, the Dutch-American company uniQure announced that it had received approval from the FDA to start the first-ever HD clinical trial that uses a virus injected into the brain carrying a gene therapy agent to reduce the amount of harmful huntingtin protein. Viruses are used in vaccines and to treat cancer. They are under study for use in HD and other diseases.

Unlike Roche's RG6042, which would require long-term and probably lifelong treatment, uniQure's gene therapy could

permanently fix the problem of HD by "altering human DNA or inserting new genetic instructions into human cells." However, it also noted that "gene therapy is a high-risk high-reward strategy. The benefits could be long-lasting – but so could any side effects."

In this Phase 1/2 clinical trial, uniQure will primarily test safety and tolerability but also whether its drug is working as designed. It plans to start enrolling clinical trial volunteers in the U.S. in the second half of this year.

FDA delays Wave trials

Another company's plans have been slowed. The FDA has delayed two Phase 1 clinical trial by Wave Life Sciences using a drug – an antisense oligonucleotide – similar to Roche's RG6042. Whereas RG6042 reduces the amount of both mutant and normal huntingtin protein, Wave's drugs target only the mutant.

"In the United States, we received approvals to proceed with the single-dose portions of both trials," a February 6 Wave prospectus states. "However, the FDA indicated to us that we cannot progress to the multiple-ascending dose portions of these trials in the United States unless we conduct an additional preclinical [animal] study and present the resulting data to the FDA for its review."

As Dr. Corey-Bloom explained, most of those Alzheimer's trials successfully removed seemingly harmful plaque from the brain, but they didn't cure the disease. Such plaque isn't a factor in HD, however, perhaps increasing hope that the Roche Phase 3 trial has a better chance of producing effective results, she observed.

An end to the 'wait and see'?

In her presentation, Dr. Corey-Bloom addressed several of the key questions about GENERATION HD1 that have emerged in the HD community, including concerns about the injection of the drug by spinal tap (lumbar puncture).

"We've had people that have probably done lumbar punctures monthly for several years, and they seem to do okay," she commented. She was optimistic that, if GENERATION HD1 is successful, Roche and physicians will seek alternatives to spinal taps. They will also pursue expanding access to the drug to presymptomatic gene carriers, she added.

Dr. Corey-Bloom ended on a positive note. "I'm always talking about things that will eventually come," said of previous talks, in which she has cautioned the HD community against unwarranted enthusiasm. "Now we actually have clinical trials, and we have clinical trials that look like they are going to be effective. That's probably the strongest statement that I've made, because I'm always trying to tell people, 'Let's just wait and see.'"

However, with the Alzheimer's trials in mind, Dr. Corey-Bloom also reminded the audience that there is no guarantee GENERATION HD1 will actually affect the disease. She crossed her fingers for good luck. We in the HD community will need to continue our hard work collaborating with her and the many other researchers engaged in the quest for treatments.

Information sources from International Huntington's Association

NOTICE BOARD

WORLD MS DAY

World MS Day is taking place on Thursday 30 May, this is a global awareness day and an opportune time for us to try to raise public awareness and understanding of MS. We will have an awareness stall at Chartwell shopping centre and need volunteers to assist with this.
If you are able to help, please phone Janet on 834 4740 or email janet@mswaikato.org.nz.

Subscriptions

Please note 2019 subscriptions are now due. The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received. Thank you for your support.

Payments

If you wish to make any payments directly to the Trust bank account this is 02 0316 0488196 000. Please remember to include your name and what the payment is for eg Subs.

Entertainment Book

MS Waikato are selling the Waikato / Bay of Plenty Entertainment books again this year. For \$65 you will receive thousands of dollars worth of vouchers in our region. Books are also available for other regions. MS Waikato will receive \$13 from each book sold. A sample book is available in the office to view.

A flyer is enclosed, to order online go to www.entbook.co.nz/1b54128 or call into the office to purchase a book.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email carolestark22@gmail.com

Dogs in Homes

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

Alinkers

MSWT has 2 Alinkers which are for client use. If you are interested in trialling an Alinker for 6 weeks please contact Liz for further information. This is open to all MS clients within our region.



Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

TravelScoot

We now have a TravelScoot available for short term loan for a donation.

For more information contact Liz, Tracey or Karen.

Donations and Bequests

Donations to MS Waikato can be made at anytime 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. Alternatively a direct link to this site is through www.givealittle.co.nz/org/MSWT.

A bequest is a gift to charity and is made through your will, please talk with a solicitor if you wish to make a bequest.

HD Awareness Stall

May is HD Awareness month. We will have an awareness stall at Chartwell shopping centre on Friday 17th May and need volunteers to assist with this. If you are able to help, please phone Tracey on 8344745 or email tracey@mswaikato.org.nz.

Library Books

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

Thanks to our Sponsors and Supporters



WDFK Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West • Anytime Fitness - Hamilton Central • Stockbridge Trust • The Gallagher Charitable Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Waikato Lyceum Charitable Trust

MSWT EVENTS CALENDAR

June 2019

| SUN | MON | TUE | WED | THU | FRI | SAT |
|-----|--|--|--|---|-----|---|
| 30 | | | | | | 1 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 2 | 3 Queen's Birthday | 4 MS Support Group Dawn to Dusk Cafe Te Awamutu 10.00am | 5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 6 MS Support Group Hamilton Cafe at Summerset Down the Lane 206 Dixon Road, 10.30am | 7 | 8 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 9 | 10 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 11 | 12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 13 ME/CFS Education Group Melville Methodist Church Bader St, Hamilton 10.30am | 14 | 15 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 16 | 17 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 18 | 19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 20 Mometewa MS Support Group 10.30am Te Aroha | 21 | 22 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 23 | 24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 25 | 26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 27 | 28 | 29 MS Walking group 9am The Veranda Cafe Hamilton Lake |

July 2019

| 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 Dawn to Dusk Cafe Te Awamutu 10.00am | 3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 4 MS Support Group Hamilton Cafe at Summerset Down the Lane 206 Dixon Road, 10.30am | 5 | 6 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 7 | 8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 9 | 10 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 11 ME/CFS Social Group at Agora Cafe Kent St, Frankton 10.30am | 12 | 13 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 14 | 15 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 16 | 17 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 18 Mometewa MS Support Group 10.30am Morrinsville | 19 | 20 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 21 | 22 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 23 | 24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 25 | 26 | 27 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 28 | 29 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 30 | 31 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | | | MS Walking group 9am The Veranda Cafe Hamilton Lake |

August 2019

| SUN | MON | TUE | WED | THU | FRI | SAT |
|-----|--|--|--|---|-----|---|
| | | | | 1 MS Support Group Hamilton Cafe at Summerset Down the Lane 206 Dixon Road, 10.30am | 2 | 3 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 4 | 5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 6 MS Support Group Dawn to Dusk Cafe Te Awamutu 10.00am | 7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 8 ME/CFS Education Group Melville Methodist Church, Bader St, Hamilton 10.30am | 9 | 10 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 11 | 12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 13 | 14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 15 MS Support Group Mometewa Matamata 10am | 16 | 17 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 18 | 19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 20 | 21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 22 | 23 | 24 MS Walking group 9am The Veranda Cafe Hamilton Lake |
| 25 | 26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 27 | 28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton | 29 | 30 | 31 MS Walking group 9am The Veranda Cafe Hamilton Lake |

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