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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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Fiona's Annual Challenge



Fiona and Jacob



My older son and I like to set ourselves a challenge to do together, normally during the Christmas holidays. 2016 we hiked a mountain a week, 2017 the Tongariro crossing, so, this year we decided to climb Mt Taranaki.

This I knew was a challenge of a different level and I trained for almost 6 months doing a 10km fun run in August (first time for that too) and hiking Te Aroha, Pirongia and the Hakarimatas.

I knew controlling how my body would react under extreme pressure was unpredictable and I had no control over that; so, I put all my energy into organizing and packing for all unexpected conditions. Jacob did complain we had too much stuff as other climbers seemed to pack much less than us. I know this mountain has taken many lives and I wasn't going to allow that to happen to us.

One of my biggest concerns was heat and I knew to do the hike in late December, January or February was not an option. The date I picked was December 18th, I was advised to wait until January as that is when the summit track is recommended and ice free.

The track; we started the climb at 7am; the first hour and a half was a steep concrete track to service the huts. That was the easy part but I did wonder what it was going to be like to come down again. After that was shingle or scree. This was the hardest part and took us over two hours. I climbed this part on hands and boots. I had gardening gloves on as I had read about his part. I found this incredibly hard, at one point I looked up at the summit and it looked quite close. In a moment of defeat and foggy thought, I shouted to Jacob to leave me behind and get to the summit without me I would wait there for him. Thankfully he didn't hear me and shouted down "Lucozade", after a quick drink and some self-talk I decided to leave my bag as Jacob had enough water, food, first aid kit and warm clothes for both of us and carried on.

Jacob pointed out later that he knew the summit was still a long way away as we had only been at it for 3.5 hours and it was a ten-hour hike. The scree did eventually come to an end and the track became large rocks to climb over which was easier and fun but, I was concerned about coming

Fiona's Annual Challenge cont...

down as my balance isn't good. Jacob was excellent in helping me down by telling me where to put my feet and or giving me his hand.

While climbing over these rocks I noticed that the marker pegs which marked the track actually had numbers which counted down and we were at number 25. This was very motivating especially when we got to number 10. We reached the top at 12pm; the crater was covered in snow, which we expected. We had brought crampons with us but had decided to use them on the scree and they had broken, there was quite a clear footprint track into the crater. We had met some other climbers near the top so I was happy for Jacob to go in, these hikers were friendly and Jacob went with them.

The summit was on the other side of the crater and involved a very steep, thickly snow covered slope which I knew was going to be exhausting and I didn't have spare energy for that. But, sitting on the side and seeing everyone else explore this snow-covered bowl was too much to bare, so I decided to risk the footprint path into the crater and look over the edges. I am glad I did, it was spectacular! The mountain reminded me of a layer cake, green patchwork paddocks, a ring of trees and bush, grey scree, dark jagged rocks and a thick layer of snow.

As many signs remind us as we go up; the summit is only half way! Coming down proved to be as challenging if not more than going up. The rocks, even though I asked Jacob to stay with me as I may need help were easy. The scree, on the other hand was as horrid coming down as going up! Jacob tried

a form of scree surfing which meant he fell over a lot. I tried cautiously side stepping, then crouching and sliding (this was not a good idea, very dusty)! In the end, sticking to the thicker parts of stone and sliding down a little with each step was effective but I did fall often and it took as long as going up.

By the time we reached the concrete, we had been walking for nine hours. The concrete as I had feared was also very tricky. There were many little stones lining the path, my body seemed to be working in super slow mode. This was the last straw for Jacob, he understood the slow climb and up until the concrete, he accepted the scree was hard and slow. The concrete in his mind was the last part and being tired should have been motivating to get to the end but no amount of complaints, encouragement or sheer stubbornness could make my legs move quicker. Jacob decided that he would take my bag (which I had collected from the scree) as well as his, give me his hiking stick so I had two and wait for me in the car.

I think that last part took him about twenty minutes. He waited in the car for an hour and then decided he had better find me in case I had fallen over. We met at the start of the track. The whole hike had taken me 11 hours; Jacob would have completed it in the 8 hours suggested but took his responsibility of staying with me seriously. He is 14 now so next year's challenge might be Mt Ruapehu but I know the years of him hiking with me are coming to an end. I know how fortunate I am having a hiking companion and having my MS controlled so well.

Fiona McLeod



Adam Muir's Kawhia Cruise

The Kawhia Cruise has now completed its sixth year and was once again an exciting and successful day.

The morning began with a little drizzle but this didn't deter the drivers, with many arriving early to enjoy the hearty breakfast that the Jukebox Diner is famous for! The drivers and supporters were very generous; making donations and purchasing raffle tickets.

The cars were magnificent with a wide variety of different classic cars, all beautiful presented. The line of over 55 classic cars snaking over the hills to Kawhia

was an impressive sight to be seen. Kawhia turned on the sunny weather and everyone settled down to a relaxing afternoon of car gazing and wonderful music from the band 'Shotgun'.

Thank you to Adam, Ashley, Josh, Kim and all the other helpers for organising a wonderful Kawhia Cruise. The event raised a total of \$2,544.



St John Health Shuttle

The Health Shuttle is a free community service that transports people to essential medical and health-related appointments, and then brings them home again. A donation is appreciated to cover costs.

The Health Shuttle service is often used by older people who live alone and no longer drive. It's also used by people who are too unwell to drive and those who can't physically access other transport options. St John Health Shuttles are not available in all areas; however, they are currently available in Hamilton, Thames, Waihi and Whangamata.

Reasons to use the service include doctor visits, dental appointments, specialist appointments, hospital day-stays for minor surgery and any other types of health appointments.

Health Shuttles run at different times, depending on what each community needs.

To find out more about St John Health Shuttle or to book a journey, call toll free on 0800 000 606.

Bladder Problems with MS

Bladder Problems with MS

There are two main types of bladder problems in MS: problems with storage and problems with emptying.

Doctors aren't sure why some people get one and not the other, or why some people get a bit of both.

If everything is working as it should, bladder control is something most people tend to take for granted.

When your bladder is getting full, a warning system between your brain and bladder tells you that you should go to the toilet – and you can usually 'hold on' until you get to one.

The muscles in the bladder need to work in coordination with each other when storing and emptying. One relaxes while the other contracts. Problems happen when something goes wrong with this system.

Problems with storage

When the nerve pathways in the spine are interrupted, even a small amount of urine in the bladder can cause it to contract. This causes a need to urinate frequently – known as frequency.

Another problem is an inability to 'hold on', called urgency. If this is severe, urgency incontinence will be a problem.

Problems with emptying

The other main type of bladder trouble is to do

with emptying. If the bladder muscles don't work in coordination, this can make urine flow poor and interrupted, and your bladder may not empty completely.

If your bladder isn't emptying completely, you may not be able to feel it. However, if you need to go to the toilet for a second time only a short while later and you're passing a similar amount of urine, this could be a sign that your bladder isn't emptying fully.

Urine left in the bladder – this is called 'the residual' – stimulates further bladder contractions and can add to problems of urgency and frequency.

Urinary tract infections

If you have bladder problems, it's important to be tested for a urinary tract infection (UTI), as the symptoms of a UTI can be very similar to bladder problems caused directly by MS – such as needing to go to the toilet frequently.

An infection can also make MS symptoms, including bladder problems, worse.

A UTI causes the urine to go cloudy and smelly, and some people may also have pain on passing urine, though not everyone.

Infections can usually be treated with antibiotics.

Source: www.mssociety.org.uk

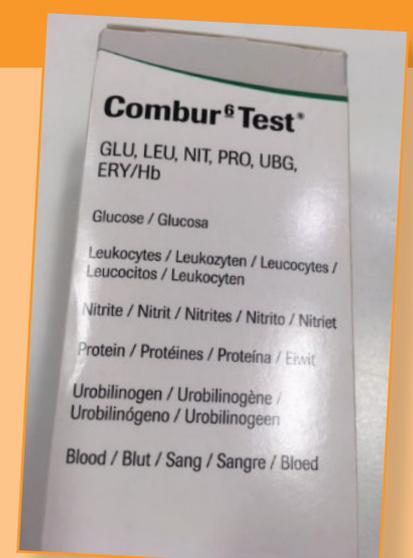
Dipsticks

Don't forget that you are now able to purchase urine dipsticks for \$27.20 for a pack of 50 from the Pharmacy on Meade, Level 1, Meade Clinical Centre, Waikato Hospital.

These may be useful if you suspect you may have a urinary tract infection and you can test your urine at home.

Please contact your GP or Neurology Outpatients if the results are positive to assess whether further action is required.

If you have any ongoing issues which are causing difficulty when you are out and about please contact Liz, she may be able to assist.



Subscriptions

If you have received a subscription notice with your newsletter, this is to remind you that your subscriptions for 2019 are due.

We received a poor response to the request for subscriptions last year with a significant number of our membership group not paying these. I am sure you will agree that our funds are better spent supporting and educating members than chasing for overdue subs.

If you have a problem in paying subscriptions, please do talk with a staff member.

You are all receiving our newsletter which is an expense to both produce and print, plus postage costs or administrative time to send electronically. We also provide support services, working closely with clients when you are unwell, and are often the link between you and the hospital or other community services. We are also providing education, support groups and exercise classes.

MS Waikato is a registered charity. Your subscriptions make a significant difference to us and ensures we are able to continue to provide these services. At this point in time you may not feel you need many of our services, however your support ensures we are here if yours or your loved ones situation changes.

Thank you to those who have paid subscriptions.

MS Base

This is the international online registry for neurologists studying Multiple Sclerosis.

If you have not yet signed up for this and would like to be part of the MSBase Registry a consent form can be obtained from the neurology department at Waikato Hospital or from MS Waikato.

If you would like to know more about MSBase information can be found at: <https://www.msbase.org/>

Additional information can be found on the New Zealand Multiple Sclerosis Research Trust website;

<https://msresearch.nz/msbase-introduced-to-new-zealand-allowing-people-with-ms-in-to-participate-in-international-research/>

The Michael Ford Memorial Charity Golf Tournament

Do you enjoy a game of golf or have family/friends who may? Do you know of any organisations who may be interested in sponsoring the tournament?

Our tournament was originally established 19 years ago by Michael Ford, a client affected by MS, who sadly passed away at the end of 2017. This is an annual event and one of our major fundraisers but we need your help for this to grow.

The tournament is taking place this year at the Ngahinepouri Golf course on Friday 5th April.

For players, entry is \$30 pp for registrations received by the 28th March, (\$40 for late entry after this date). This includes morning tea, sausage sizzle and a soft drink on the course. It is a stableford tournament with divisions for men, ladies and non-golfers with a great range of prizes to be won. Registrations and morning

tea 10.00am, with a shotgun start at 11.00am.

For sponsors, we offer a range of sponsorship to suit different organisations. Gold sponsorship is \$400, this includes hole sponsorship with tee signage, includes a team entry and the opportunity to display your own banner. Silver sponsorship is \$200 with an opportunity to display your own banner. Bronze sponsorship is for other donations or prizes for the players. All sponsors are acknowledged at the event, in our newsletter and on our website for a year. All sponsors also receive a certificate of sponsorship as appropriate – gold, silver or bronze.

For more information on participating or sponsoring the event please contact Janet on 07 834 4740 or email janet@mswaikato.org.nz

All funds raised are used to directly assist with the provision of support services for you, our clients.

Multiple Sclerosis Waikato AGM

The AGM will be taking place on Thursday 21st March, 6.30pm in the Life Unlimited Board Room. Financial members will be entitled to vote. To reserve a seat please email janet@mswaikato.org.nz by Tuesday 19th March.

HD News

Hello 2019! I hope you all had wonderful Christmas and New Year celebrations, and stayed safe and dry.

Before looking ahead to this year, a wee recap of the end of 2018 is required. We finished the year on a high after research Fellows from the Centre of Brain Research, Dr Nasim Mehrabi and Dr Malvinder Singh-Bains presented to our HD community "Pushing the Research Frontiers to Unlock the Secrets of Huntington's Disease" along with an update on HDYONZ.

What a fantastic night! Our families received a good dose of hope hearing about the brilliant research our talented doctors are undertaking right here in NZ. We also learnt more about the ground-breaking gene lowering research. It was exciting to hear about the different research that is happening around the globe regarding alternative ways to administer drug therapy to achieve success in the battle against the protein that causes Huntington Disease.

Many family members lingered on afterwards to catch up and chat with others over supper. The presentation can be found on our website <https://www.mswaikato.org.nz/library-resources/hd-publications>.

Our HD Family Day at Totara Springs in Matamata was such a success in 2018 that we have decided to make this an annual event. Our next event is on

Saturday 6th April 2019, please see the notice below. To register please phone Tracey on 07 8344745 or email tracey@mswaikato.org.nz by 8th March.

We are also continuing to plan regular coffee group catch-ups for different groups - families, carers and young people. We are looking to offer our local young people a variety of support networks, connecting them with others both locally and nationwide and to achieve this we will be inviting key figures from HDYONZ to join us.

So, an action packed 2019 awaits. If you are impacted in some way by HD, live in the Waikato region and would like to join in, or require support, please contact Tracey Larsen on 07 8344745, 027 385 5425 or email tracey@mswaikato.org.nz.

Tracey Larsen



Dr Nasim Merabi, Dr Malvinder Singh-Bains, Peter & Janelle Knox, Tracey Larsen

ME/CFS & 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.

You and your family are warmly invited to our

HD FAMILY DAY OUT

The day will provide a lot of fun and laughter and an opportunity to connect with others, so will be a great day out for the whole family and carer's.

At Totara Springs Matamata

**On Saturday 6TH April 2019,
10am to 4pm**

Cost: \$10.00 per person

Any donations above this amount will be greatly appreciated

Morning Tea, Lunch and Afternoon Tea will be provided

Please phone or email to register by Friday 8th March 2019.

Ph: 07 8344745

Email: tracey@mswaikato.org.nz

We look forward to seeing you all there

NOTICE BOARD

22nd Annual Zoo Day

Hamilton Dinsdale Lions Club in conjunction with Hamilton Zoo and Friends of Hamilton Zoo invite you to the 22nd Annual Zoo Day
A day of fun at HAMILTON ZOO

For people with disabilities and their immediate caregiver (one only)
Sunday 31st March 2019
10.00am - 2.00pm

Gold coin entry fee applies to support conservation projects at the zoo.

We require an indication of numbers attending.
RSVP to dinsdalesecretary@gmail.com by March 22nd 2019
Musical Entertainment and refreshments will be provided

Show your Ability

2019 Disability Equipment Expo
Claudelands Event Centre
Wednesday 27th February, 9 - 3pm
Entry is Free

TravelScoot

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

Alinkers

MSWT has 2 Alinkers which are for client use.



If you are interested in trialling an Alinker for about 6 weeks please contact Liz for further information. Please understand that there is an expectation that you will keep track and report your usage for a 4 week period while you have the Alinker. This is open to all MS clients within our region.

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.

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

Entertainment Book – 2019/2020

The 2019/2020 edition of the Entertainment book will be available in the last week of March. Pre-sales (with the bonus vouchers) should be available within the next couple of weeks. We will notify you as soon as these are available, keep an eye on your inbox!

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.

Wheelchairs

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

Thanks to our Sponsors and Supporters



WDFW 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 • Ngahinepouri Golf Club • Waikato Lyceum Charitable Trust

MSWT EVENTS CALENDAR



March 2019

SUN	MON	TUE	WED	THU	FRI	SAT
31					1	2 MS Walking group The Veranda Cafe, Hamilton Lake 9am
3	4 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	5 MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	7 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	8	9 MS Walking group The Veranda Cafe, Hamilton Lake 9am
10	11 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	12	13 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	14	15	16 MS Walking group The Veranda Cafe, Hamilton Lake 9am
17	18 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	20 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	21 MS Support Group Te Aroha, Mometewa 10.30 am AGM Life Unlimited Building Board Room 6.30pm	22	23 MS Walking group The Veranda Cafe, Hamilton Lake 9am
24	25 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	26	27 MS Exercise Class MS Support Group Absolute Café Cambridge 10.am	28	29	30 MS Walking group The Veranda Cafe, Hamilton Lake 9am

April 2019

SUN	MON	TUE	WED	THU	FRI	SAT
	1	2 MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	5 The Michael Ford Memorial Charity Golf Tournament Ngahinepouri Golf Club	6 MS Walking group The Veranda Cafe, Hamilton Lake 9am HD Family Day
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	12	13 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 MS Support Group Morrinsville Mometewa 10.30am	19 Good Friday	20 MS Walking group The Veranda Cafe, Hamilton Lake 9am
21	22 Easter Monday	23	24 MS Exercise Class MS Support Group Absolute Café Cambridge 10.am	25 ANZAC Day	26	27 MS Walking group The Veranda Cafe, Hamilton Lake 9am
28	29 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	30				

May 2019

SUN	MON	TUE	WED	THU	FRI	SAT
			1	2 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	3	4 MS Walking group The Veranda Cafe, Hamilton Lake 9am
5	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	7 MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	9	10	11 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 MS Support Group Matamata Mometewa 10.am	17	18 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 The Veranda Cafe, Hamilton Lake 9am
26	27 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	28	29 MS Exercise Class MS Support Group Absolute Café Cambridge 10.am	30 WORLD MS DAY	31	

Please cut here

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