

Multiple Sclerosis Waikato

Issue 58 - August 2018

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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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Mahi tatau ki te whakawhiwhi he hapori rawe

Walking the walk





Those of us who are of a certain age will remember a 15-year-old Helen Shapiro belting out her hit song `Walking back to happiness'. Well Lisa Andrew of Hamilton is literally doing that and wants to get more of us involved.

Lisa was diagnosed with remitting/ relapsing MS in 2007 following an episode on Christmas Eve which saw her wind up in A&E. " In some ways I was really lucky" says Lisa "By coming in through A&E I got into the system quickly and ended up getting a quick diagnosis". Lucky or not Lisa's first reaction to the news was that she had somehow failed. However, she says she has learnt along the way that you have to change how you think and feel about MS and yourself - treat it as a positive. "Looking back over the years since my diagnosis I feel blessed. Having MS has, in many ways enriched my life. I wouldn't be where I am today without the journey".

Last year Lisa's family were going through a `tough patch' - "I got really down and quite depressed". Lisa had joined an organisation

called `Park Run'* last August and had been turning up every Saturday morning (rain or shine) and walking a minimum of 5 k/m around Hamilton's Lake Rotoroa. One night she decided to do something and set herself a challenge – a 100-day challenge – to walk at least 5 k/m a day for 100 consecutive days.

On the second day of her challenge. she joined Sue Dela Rue and her supporters to walk over Mt Maungatautari ManuScript (see issue 53).Lisa completed her 100 consecutive walks on 31 December 2017 and just kept going, eventually completing 215 davs she rolled her ankle doing the Colville half marathon. During that period she had completed 10 half marathons and is aiming to complete 12 half marathons this year. Those half marathons include Hamilton, Taranaki, Colville, Huntly, Ohakune, Rotorua, Mt Maunganui (at night), Auckland and Taupo. Lisa says these walks are not just walking - it's a way of re engaging with life. "I've really surprised myself and it is both challenging and fun. I've met lots of

ms.

Walking the walk continued

different people – and you don't just meet them – you get time to chat and really get to know them."

From a purely performance point of view Lisa has improved her times for the off-road 22.1km half marathon from 5 hrs 20 minutes for her first to 3 hrs 55 min for her most recent. She says "It doesn't matter how slow you are you're still lapping people on the couch".

Following a day spent at a seminar run by MS Auckland Lisa has also totally changed her diet to a whole food plant based diet and is noticing the benefits it provides.

Spurred on by her experiences Lisa in conjunction with Liz from MS Waikato, has started a walking group for people with MS at Hamilton Lake at 9.00am on Saturday mornings as detailed below.

* Park run is an organisation started in England 12 years ago to bring communities together. The runs are now held all over the world. For more info look on www.parkrun.co.nz. Ian Maxwell

MS Walking Group

The walking group led by Lisa Andrew meets every Saturday morning – rain or shine, to walk around Lake Rotoroa (Hamilton Lake).

The group meet outside Veranda cafe at 9.00am. All are welcome to come along and join in, bring your family or friends; there is no need to preregister for this. The path is flat and suitable for wheelchairs, pushchairs and Alinkers. Lisa will be wearing an MS t-shirt.

If you want to come along but feel a little shy, give Liz a call, she may just come along and walk with you!

The group also enjoy a coffee together after the walk; if you can't make the walk but would like to go for a coffee you are welcome to join them around 10.00am at the Veranda café.







Client Survey

MS Waikato strives to provide a service of excellence. To enable us to do this effectively it is essential for us to conduct regular client surveys. As a not for profit organisation we are dependent on grants and fundraising to provide our services. We want to ensure that the funds we do have are used effectively. This is your opportunity to let us know your views, how you rate the services provided and if you have any comments or feedback you would like to share with us, perhaps about our staff, services, resources available, newsletter etc. The survey is anonymous.

For those of you who have provided us with an email address this will be sent to you via email with a link to complete this online. If we don't have your email address a survey and envelope for return will be included with this newsletter. Please complete the survey and return to us by the 3 September.

If you have any questions or difficulty in accessing the survey please contact Janet on 07 8344740 or janet@mswaikato.org.nz . Thank you for your support.



Get those Endorphins working for you

Take a look at how your daily exercise routine can bring enormous benefits to wellbeing and MS.

Well-being is a multifactorial state of health and self-existence, this is individual and can be seen in many different ways including: mental and physical health, relationships, and overall quality of life. We have previously covered a lot of the benefits that physical activity has on our physical health including; strength, cardiovascular health, and a reduction in MS associated symptoms. What doesn't get talked about a lot is the benefits of physical activity on your mental health.

Depression is commonly observed in people with MS, and has been associated with lower quality of life scores. Participation in regular physical activity is a potential way to assist in the management of depression. There has been strong evidence previously in non-MS populations that suggest those individuals who participate in regular physical activity are less likely to suffer from depression and show the associated improvements in quality of life scores. More recent studies demonstrate that physical activity in patients with MS reduce the occurrence of depression and fatigue and positively influence quality of life.

How does exercise help with mental health?

When we are regularly physically active our bodies release endorphins (neuropeptides - natural pain and stress relievers) into the body, these endorphins have been shown to assist in the management of depression, stress, anxiety and other emotional difficulties that may be brought on through living with MS and or just general daily life. Other mental health benefits of exercise include improved selfesteem, as our bodies release endorphins it triggers a positive feeling in the rest of the body. Endorphins also act as analgesics, meaning they diminish the perception of pain and as sedatives, assist in sleep. It is understandable that people with MS may not be as physically active as they should be for many reasons but it is clear that the benefits both physically and mentally will improve well-being. With appropriately prescribed exercise programs; taking into account the individual's abilities, many mental health benefits may occur, including:

- · Reduced Stress
- Reduced rates and feelings of depression
- Decreased pain
- Increased self-esteem

- Improved quality of life scores
- Decreased levels of anxiety
- Improved sleep

All of these benefits are liked to improving a person's well-being. Strong social networks are also associated with increasing self-esteem and well-being so joining a group exercise class may be beneficial or exercising with a close friend and family member will assist with emotional support. Remember regular physical activity will be different for everyone so if you do not have a physical activity regime start slow and build up or see an exercise physiologist or your physiotherapist to assist with getting you started.

Any exercise is better than no exercise.

Adam Browne - MS Australia

REFERENCES

Stroud, N., & Minahan, C. (2009). The impact of regular physical activity on fatigue, depression and quality of life in persons with multiple sclerosis. Health Qual Life Outcomes, 7(68).

MS Exercise Class

MS Waikato runs a twice weekly exercise class at Anytime Fitness, corner of Anglesea and Clarence St. Each class lasts an hour with professional instruction provided by Margaret Thomson and support also provided by our volunteers Richard and Sue. Clients follow their own individual exercise programme which is developed to suit an individual's needs.

If you would like more information or wish to register for the classes please contact Liz, Karen or Tracey.

All attendees must be financial members; with a fee of \$2 per session. If attending as a non-financial member the cost is \$5 per session.

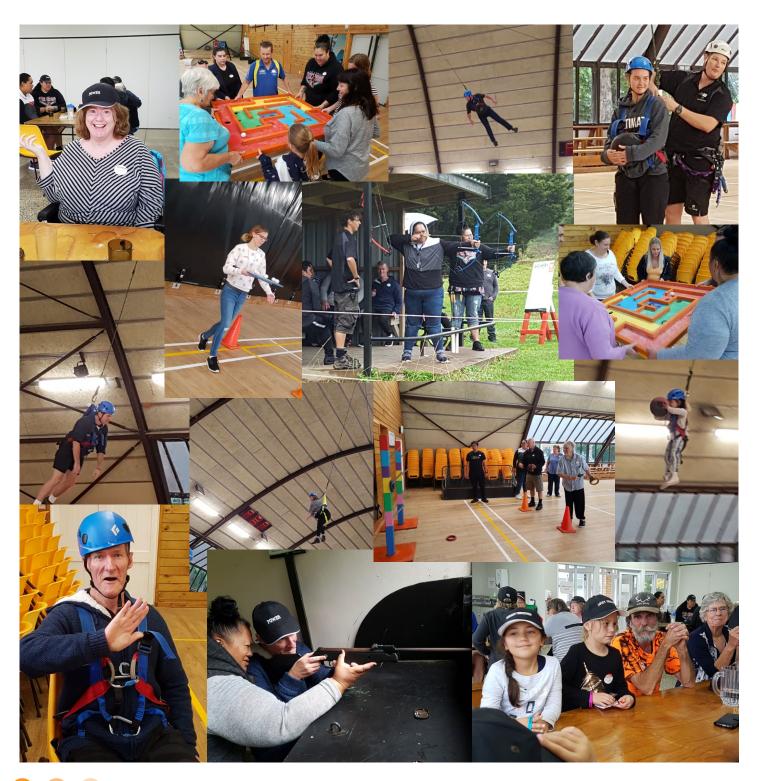
ms.

HD Family Day

MS Waikato hosted a HD Family Day at Totara Springs in Matamata in May. We had a great turn out despite the weather and the activities on offer catered well for all ages and disabilities. The day started with top town games, which provided some great laughs and an opportunity for everyone to participate and mingle. The rock wall offered an amazing challenge and enabled some to conquer their fear of heights. It also made for a great spectator's event as many encouraged their family members to achieve beyond their comfort zone.

The instructors were really accommodating, especially at the Archery and the Flying Kiwi events, enabling and encouraging everyone to participate. Daniel from HDYONZ also came down and enjoyed the day, participating and meeting our young people. Feedback received was that everyone thoroughly enjoyed the activities, the day as a whole, and the opportunity to meet other HD families. Due to the success of the day we will now endeavour to make this an annual event.

Tracey Larsen







HD News

May was certainly a busy month. My colleague Karen Bird and I attended the HD Conference in Auckland in early May. All the presenters were excellent, sharing details of the great research efforts both here in NZ and around the globe. The charismatic and inspiring Charles Sabine, BBC war correspondent, added an extra wow factor sharing video clips of the HDdennomore initiative to raise global awareness that included last year's event, An Audience with the Pope. I don't think there was a dry eye in the house; at the least I know mine were welling up in recognition of the historical significance of this event. Truly awe inspiring!! To view click on http://hddennomore.com.

Following the theme of HD Awareness month, MS Waikato held an information stall at Chartwell Shopping Centre and a display in the Dinsdale Library. Hamilton City Council was also supportive and accommodating of our request to light up Anzac Parade Bridge in HD colours to support the global initiative '#Lightitup4HD'.

Looking forward, we are still in the planning stages for our annual HD Education Evening; this will be held in the spring when the weather warms up again. We have also been in contact with HDYONZ and a youth event may well be on the cards before the year's end.

I hope everyone is keeping warm and healthy during this cold winter.

Tracey Larsen



Anzac Parade Bridge Photo courtesy of Stuff

Make a Bequest to MS Waikato

A bequest is a gift made through your will, giving you the opportunity to acknowledge the worthwhile and ongoing work of MS Waikato.

A bequest enables the gifting of property, an insurance policy, cash or other assets from your estate to the specified recipient. Of course your loved ones come first, but even just a small gift in your will could help us improve the lives of others.

It is so untrue that only the well off leave money to charities when they pass away. The reality is that without the gifts left in peoples wills, many of the charities would not survive or exist.

For some people, making a bequest through their estate is the only way they will be able to make a significant contribution to an organisation they support. A gift in your will is one way to leave a lasting legacy that will

continue long after you are gone.

If you would like to leave a lasting legacy to MS Waikato please include a bequest to the Trust in your will. We strongly recommend you seek legal advice from your solicitor when adding a bequest to your will.

Having a will is important as it allows you to say how you want your property to be dealt with when you die. If you don't have a will the law will determine how your estate is divided, and may cause your loved ones more heartache if they are not able to sort things in accordance with your wishes.

For more information on making a will you can visit http://www.lawsociety.org.nz/news-and-communications/guides-to-the-law and view the section 'making a will and estate administration'.

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.

Knowing your Rights

It is important to know your rights when receiving a health or disability service. The Health and Disability Commissioner is an independent agency which was established to:

- Promote and protect the rights of consumers who use health and disability services
- Help resolve problems between consumers and providers of health and disability services and
- Improve the quality of health care and disability services

The Code of Rights establishes the rights of consumers, and the obligations and duties of providers to comply with the Code. It is a regulation under the Health and Disability Commissioner Act.

You have the right to:

- Be treated with respect and privacy
- Fair Treatment
- · Dignity and independence
- Services of an appropriate standard
- · Effective communication
- Be fully informed

- Make an informed choice and give informed consent
- Support
- Rights in respect of teaching or research
- Your complaints being taken seriously

The code gives rights to all consumers, and places obligations on people and organisations providing services. It covers a wide range of providers (whether public or private) including:

- Hospitals
- Doctors
- Counsellors
- Nurses
- Optometrists
- Rest Homes
- Home Care providers

Most good health and disability services will have a copy of these rights on their wall or in a brochure together with information on advocates should you require one. MS Waikato has copies of these too.





NOTICE BOARD

MS Awareness Week

MS Awareness week runs from Monday 3 September to Sunday 9 September. We need volunteers to help on our stalls in Hamilton, Cambridge, Morrinsville, Te Awamutu and Whangamata. Do you have a couple of hours you could spare? Perhaps you may have friends or family who would assist with a stall too. Alternatively, you may like to organise a fundraiser or stall yourself.

These stalls are an opportunity to help raise public awareness and understanding of MS as well as an opportunity to fundraise. As a not for profit organisation we are dependant funding and fundraising simply to provide our services. If you are able to assist in any way, please phone

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

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. 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.

Kawhia Cruise

Join us for Adam Muirs Annual Fundraiser on Sunday 11th November; the cruise is now in its 6th year. Starting with breakfast at 8.00am at the Classics Museums Jukebox diner, 9.30 am leave the museum for Pirongia 10.00 am start at Pirongia for those wishing to join the rally 11.30 am arrive at Oparau Roadhouse for lunch We will then cruise onto Kawhia for prizegiving and to enjoy music from 'Shotgun', the classic rock band who will perform at Kawhia from 1.30pm. To take part 'put a note in the bucket'! All funds raised to be donated to MS Waikato For more information email

Vitamin D3

Adam - info@kawhiacruise.com

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

LiveWiseMS

Live Wise MS is a new resource for those affected by Multiple Sclerosis.

'LiveWiseMS is not only sourced by trusted medical content but it is reviewed and approved by the International Organization of MS Nurses (IOMSN), a well-respected organization of nurses who focus solely on the care of those affected by multiple sclerosis.'

To access this go to: www.livewisems.org

Entertainment Book - 2018/2019

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.

To order online go to www.entbook.co.nz/1b54128 or call into the office to purchase a book.

Subscriptions

Please note 2018 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.

MS Education Evening

Neurologist Jan Schepel will be talking about the latest MS Treatments, Symptom management & Research Thursday 18th October, 6.30pm The Link (corner River Road and Te Aroha Street) Followed by a light supper

Dogs in **Cambridge MS Support Group Homes**

A support group is being set up in Cambridge. The group will be meeting on the last Wednesday of each month at the Onyx Café, Alpha St, at 10.00am. If you have any questions please ring Karen on 07 8344742.

Thanks to our Sponsors and Supporters

For the safety of

our staff please

ensure all dogs

are secured when

staff visit.

Wheelchairs

MS Waikato

has wheelchairs

available for

loan, for all

enquiries phone

07 834 4740.





























WDFF Karamu Trust • Waipa District Council • COGS- Hamilton City, Hauraki, South Waikato & Waikato West • Anytime Fitness -Hamilton Central • Stockbridge Trust • Riverside Golf Club • The Sutherland Self Help Trust • The Gallagher Charitable Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Glenice and John Gallagher Foundation • The Hamilton Club

MSWT EVENTS CALENDAR

MOWI EVENIO GALLIDAN								
September 2018								
SUN	MON	TUE	WED	THU	FRI	SAT		
30 NS	Awar	eness	week	3-9 Se	ptemb	1 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
2	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	7	8 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
9	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	ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	14	MS Walking group The Veranda Cafe, Hamilton Lake 9am		
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 MS Support Group Te Aroha Mometewa 10.am	21	MS Walking group The Veranda Cafe, Hamilton Lake 9am		
23	24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25	26 MS Exercise Class MS Support Group Onyx, Alpha St Cambridge 10.am	27	28	29 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
October 2018								
SUN	MON	TUE	WED	THU	FRI	SAT		
	MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	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	6 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
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	ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	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	MS Support Group Morrinsville, Mometewa 10.am MS Education Evening Te Aroha St, Hamilton, 6.30pm	19	20 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
21	22 Labour Day	23	24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25	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	MS Exercise Class MS Support Group Onyx, Alpha St Cambridge 10.am					
November 2018								
SUN	MON	TUE	WED	THU	FRI	SAT		
				MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	2	3 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
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 10am	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	9	MS Walking group The Veranda Cafe, Hamilton Lake 9am		
Lassics Museum Juke Box diner 8.00am	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 Matamata Mometewa 10.am	16	17 MS Walking group The Veranda Cafe, Hamilton Lake 9am		
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 The Veranda Cafe, Hamilton Lake 9am		
25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27	MS Exercise Class MS Support Group Onyx, Alpha St Cambridge 10.am	29	30			