

Totara Springs 2016

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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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MS Waikato organised another great camp at Totara Springs in March of this year. The camp was well attended by people with MS, their partners and children; feedback from everyone was that it was a special time together renewing old friendships and making new ones.

The camp works well on many levels, apart from being a fun challenging time it is also an opportunity for people with MS to discuss their joys and woes, hopes, fears and dreams. Many good ideas are shared and the participants said it is encouraging to be with others facing a similar path in life. There is also a special opportunity for partners of people with MS to be together and over the weekend there is informal opportunity to ask each other questions and share experiences. For the children of people with MS it is a rare opportunity to be in a place where everyone's parent has MS so it is completely normal and they too have a chance to talk openly about MS.

While most of the weekend is spent enjoying activities, whether participating or observing, some time on Saturday night is put aside for the older kids to have a session of talking about MS and learning about it in

a supportive and positive way. The activities we participated in included; kayaking, shooting, rock climbing, hydro slide, flying fox, swimming, team games, BMX, go carts, crate climbing, rock climbing, archery, tubing, slippery slide and mini golf and as you can see from the photos a wonderful time was had by all!

The actual environment is beautiful, set just out of Matamata with beautiful views and lots of birdlife. The rooms are lovely and the staff couldn't have done more to make us comfortable and welcome. We hope to run the camp again 16-18th March 2018, keep the weekend free.



ManuScript is brought to you by:





Totara Springs was my first camp, and what a great time I had. As you can see from all the photos there were many wonderful activities to have a go at, some challenging and some just great fun! Being an MS Helper was a great reason why I couldn't participate in some of the challenging activities. My heart was in my mouth as I watched you all coming down the waterside at 100mph! In control you said, but I was sure someone would fly out into the bush. I learnt who loved speed in the go -karts and BMX and who was fearless in the flying fox, the crate climbing and rock wall.



It was amazing to see the teamwork that formed in the top town games. You would only get a little wet they said as the water poured over us while we tried to block holes in a drain pipe! The participation, comradeship and encouragement everyone gave each other was great to see. The banter, laughter and friendships formed were inspiring. It was lovely to be part of a great weekend and I look forward to doing it all again. (Maybe I'll be brave enough to have a go on the waterslide next time!)

MS Helper © Karen Bird





MS Waikato would like to thank the New Zealand Community Trust and the Rehabilitation Welfare Trust for their generous support in assisting to fund the camp.

Liz's Marathon Fundraiser for MS

A huge thank you to everyone for your support for the marathon fundraiser.

Liz completed the Rotorua marathon in 5 hours and 15 seconds and raised over \$3,000 which will be used for client services.

Check out her running shirt!



The Michael Ford Golf Tournament

On Friday 4th March we held our annual golf tournament; the event is one of our major fundraisers. Established by one of our clients, Michael Ford, our tournament has now running for 16 years.

This year was a particularly hot day for the event but with our field of 44 players, we had a very successful and enjoyable day and raised a total of \$6,087.

Overall best stableford was awarded to Myles Needham.

The event wouldn't be possible without the support of our sponsors, players and volunteers; some of whom have been supporting us since the tournament first began. In particular we would like to thank the Riverside golf club and Kerry Kirk for their support too.

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 you, our people.

Thank you to our sponsors, please do remember them and support them too.



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- Hamilton Wholesale Meats

Gravity and the 'F' word

I was diagnosed with Primary Progressive MS in 1999. Sometime later when attending a Rehab clinic I was asked what my goals were. My eldest son had just started school and I had two pre-schoolers at home. I had one simple goal – to stay on my feet until they finished school and didn't need me. At the time it was a pretty ambitious goal as my MS appeared to be progressing quite quickly. I'm writing this in the last week of October. Yesterday, my youngest son finished school. What do I do now? I've spent the last 16 years refusing to give in to this disease and now having achieved my only goal I'm a bit lost.



It seems the easy option will be to just give in and put my feet up. I've got the full set of mobility accessories – stick, walker, wheelchair and recently a scooter – it's not the silliest idea I've had recently. But my dear wife has helpfully informed me that, as far as she is concerned, that is not an option and she has plans to utilise what extra spare time we may have and that doesn't include sitting around watching the tele! Ah well, I guess it's back to the drawing board.

As I mentioned I've got the Progressive form of our wonderful disease and over the years I have steadily got less steady on my feet and find it quite difficult to retrieve items that have fallen, or reside, on the ground. Thanks to our good friend Isaac Newton we are all too well aware that when you drop something, or knock something over, gravity will make sure that it is going to end up on the ground. Thanks to my current condition retrieving such items involves a

series of ungainly, and definitely uncoordinated movements, and the assistance of any inanimate objects that may be in the near vicinity. The regularity with which things end up on the floor is getting a tad annoying not to mention tiring. My dear wife arrived home one day with one of those hand operated claw thingy's that you use for picking up things on the ground. It has proved useful but that has brought about its own frustrations – with some 13 rooms in the house it is inevitably not the room this

apparatus resides in that you actually drop something. Then you have the decision to make – drag yourself off to find it or do the dance and try and get down to pick up what you've dropped. I know – the obvious answer is to have more than one. I've got four walking sticks in the house but somehow they always end up in the same room together – just another frustration.

Ah yes – frustration – the 'f' word. Of all the things that come with having MS – lack of control of your body, inability to do 'normal' things like running or climbing ladders, the pain, loss of dignity as you take another dive – it's the frustration of not being able to do the simple things in life that really gets to me. And yes, I know in my current state I am a lot better off than many of you reading this. But hey, I'm feeling a little melancholy today – my kids are of an age they don't need me anymore and we're on the verge of another long hot summer – oh joy! Sorry about the whinge but I feel a bit better for it. Now – about those goals ...

Ian Maxwell

Bryant Retreat for Women

'Whare Hauwora Waahine – Healing home for Women'

The Bryant Retreat for Women was established in the 1950's and has provided a haven for rest and relaxation ever since. It is fully funded by the DV Bryant Trust.

The retreat was created to provide an environment in which women could rest and relax in quiet calm surroundings. Situated on the waterfront of the inner Raglan harbour, the tranquil location is a stress free space with its extensive gardens, spacious lawns and stunning views of the harbour and the hills beyond. Guests are within easy walking of the Raglan wharf and town shopping centre.

The retreat accommodates up to six women at any one time for a stay of 11 eleven nights. There is no charge, the Bryant Trust funds all the accommodation costs. You are not expected to do any housework, cooking or other chores. Other than being present at the three freshly prepared meals each day, time at the retreat is largely yours to enjoy as you wish.

If the retreat is something you would benefit from please talk with your GP or our client services staff. Referrals must be done through your GP and forms can be downloaded from the DV Bryant website www.bryanttrust.co.nz

ME/CFS & FM Updates

February's education support group meeting presented Neil Micklewood, Psychologist, who helped us to understand how psychological distress accompanies illness through mind/body connections. He explained that in the case of chronic illness, often the repeating patterns of our approach and attitude to the illness can be detrimental to wellness and keep us stuck in the unwellness cycle. A psychological approach can therefore help us to examine our beliefs, patterns and approaches and assist us to find strategies that create change in our perspectives, enhancing our quality of life within the constraints of chronic illness and in turn supporting a sense of wellness.

Toni from Life Unlimited visited the support group in March presenting and demonstrating aides to support daily living. She had some wonderful items on display from kettle holders for safe pouring, shower stools, long handled grabbers and tools for passive exercise, to back washers, book pillows, utensils with large easy grip handles and tools to help open jars and cans. Come and have a look at the store at Life Unlimited if you have difficulty with daily chores, personal care or mobility; they have a great product range. Alternatively, check out their website and online store at <http://www.lifeunlimitedstore.co.nz>

I asked everyone to bring along one item or practice that supports their health, plus one burning question that they would like to have answered to the April

support group meeting. A great deal of relevant ideas and information was imparted which everyone found very useful, especially around supplements, practices of resting and pacing and ideas regarding meal replacement products when fatigue overrides the ability to prepare a good healthy meal.



ME CFS group

Over the next few months we have Erica the counsellor speaking to us about loss and grief with regards to chronic illness, a herbalist is coming to share her knowledge regarding a herbal approach to health, and an exercise consultant will be speaking about the importance of exercise and best ways to approach exercise when experiencing a chronic illness.

Tracey Larsen

HD News

Gene-silencing drug progresses to human trials

Isis Pharmaceuticals has initiated a phase 1/2a trial of an antisense drug, ISIS-HTTRx—the first therapy to enter clinical development that is designed to address the genetic cause of HD directly, by targeting huntingtin RNA and so reducing the production of the huntingtin protein. It is administered via lumbar puncture and travels to the brain via the cerebrospinal fluid. Inside the brain, it binds to and destroys huntingtin messenger RNA (mRNA), resulting in decreased production of huntingtin protein. Preclinical research in animal models of HD has demonstrated that lowering huntingtin mRNA and protein levels with an antisense drug slowed disease progression, increased survival and resulted in improvements in physical symptoms. Isis Pharmaceuticals has partnered with Roche to develop ISIS-HTTRx. “If this first-in-human trial proves the drug is safe, we look forward to continuing our successful partnership with Roche to bring the drug to market” said C. Frank Bennett, Ph.D., senior vice president of research at Isis Pharmaceuticals.

Information sourced from: *EHDN News November 2015 issue 26*
<http://www.euro-hd.net/html/disease/archive/ehdn-newsletter-nov2015.pdf>

NATIONAL HD CONFERENCE

When: 14th & 15th May 2016

Where: Waipuna Hotel & Conference Centre, Auckland

To register please contact:
 Huntington's Disease Association
 (Auckland) Inc.

PO Box 16 181, Sandringham,
 Auckland 1351

Email: admin.hda@vodafone.co.nz

Phone: 09 815 9703

www.hdauckland.com.nz

NOTICE BOARD

Help 'Kiss Goodbye to MS' with our annual appeal

MS Waikato will have stalls within the Waikato on Thursday 26 and Friday 27 May. We need volunteers to assist with this, if you are able to help, please phone Janet on 8344740 or email janet@mswaikato.org.nz

The stalls are valuable in raising public awareness and understanding of MS. World MS Day also takes place on Wednesday 25 May and is a global awareness day.

MS Education Evening

Our annual education evening will take place on Wednesday 18th May, 6.30pm at the Link, corner of Te Aroha St and River Rd.

Neurologist Jan Schepel will talk about diet, exercise and medication; this will be followed by a light supper.

To reserve a place please call 8344740 or email mswaikato@mswaikato.org.nz by Friday 13th May.

The Entertainment Book

MS Waikato are selling the Waikato/ Bay of Plenty Entertainment books again this year. For \$60 you will receive thousands of dollars worth of vouchers in our region. Books are also available for other regions.

MS Waikato will receive \$12 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.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email peterandcarole@xtra.co.nz

Subscriptions

Please note 2016 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.

Bank Account

Please note our bank account has now changed, our account number is now: 02 0316 0488196 000. If you pay your subscriptions directly and have previously saved our account details, you may wish to amend this now.

Achilles

Achilles International New Zealand provides New Zealanders with disabilities the opportunity to participate alongside able-bodied athletes in local mainstream events. For more information, go to: www.achillesnewzealand.org.

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.

8076 B & B

Fancy getting away for a night or two? Jo and Sandy Sanderson's B& B in Hikutaia contains a two bedroom unit, and is specifically designed to accommodate a wheelchair. It is only 200 metres from the Hauraki Rail Trail, is ideal to enjoy a walk (no hills) or you may like to borrow one of their bikes.

Mention MS Waikato when you book your break and Jo and Sandy will donate \$15 from the nightly rate to us. If you are interested please view their website www.8076.co.nz

To make a booking ring Jo on 078624943 or email Jo_banb8076@yahoo.co.nz, and mention MS Waikato (please don't use the online booking calendar as they won't know the booking is for MS people).

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Rehabilitation Welfare Trust • The Norah Howell Charitable Trust



MSWT EVENTS CALENDAR

JUNE 2016

SUN	MON	TUE	WED	THU	FRI	SAT
			1 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	2	3	4
5	6 <i>Queen's Birthday</i>	7 MS Support Group Te Awamutu 10am Dawn till Dusk	8 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	9 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	10	11
12	13 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	14	15 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	16 MS Support Group Mometawa Te Aroha 10am	17	18
19	20 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	21	22 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	23	24	25
26	27 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28	29 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	30		

JULY 2016

SUN	MON	TUE	WED	THU	FRI	SAT
31					1	2
3	4 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	5 MS Support Group Te Awamutu 10am Dawn till Dusk	6 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	7	8	9
10	11 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	12	13 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	14 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	15	16
17	18 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	19	20 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	21 MS Support Group Mometawa Morrinsville 10am	22	23
24	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26	27 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28	29	30

AUGUST 2016

SUN	MON	TUE	WED	THU	FRI	SAT
	1 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	2 MS Support Group Te Awamutu 10am, Dawn till Dusk	3 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	4	5	6
7	8 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	9	10 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	11 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	12	13
14	15 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	16	17 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	18 MS Support Group Mometawa Matamata 10am	19	20
21	22 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	23	24 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	25	26	27
28	29 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	30	31 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton			

Please Cut Here

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