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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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Hollys Run for MS

Holly Pass ran Hamilton's 'Round the Bridges' 6 km fun run in November to raise money for MS Waikato.

Holly has the relapsing/remitting version of MS. She was diagnosed in Tauranga in April 2013 aged 26. It doesn't sound right but Holly was lucky - she was diagnosed quickly!

Holly got the tell-tale tingling feeling in the fingers coupled with feeling fatigued. When her GP inquired about her family history and discovered her mum had MS he sent her off for tests at Tauranga hospital. Following an MRI scan and the good ole lumbar punch Holly was told they had found scarring on the nerve ends and MS was diagnosed. She was put on a treatment of steroids for 10 days and the symptoms appeared to go away.

In October 2014 Holly had a relapse while working as a Personal Trainer at Hamilton gymnasium 'City Fitness'. "My eye sight was affected; I had vertigo and had periods of depression. The relapse lasted about eight weeks after steroid treatment for 10 days. "Although there were initial signs of improvement I struggled to bounce back to my normal hyper happy self" she says. "It took the Neurologist team about six months to figure out the right treatment" Holly was put on a daily dosage of 'Copaxone' in April 2015 and after initial side effects was soon feeling well enough to return to work."

Holly heard about 'Round the Bridges' from some of her clients who were doing the run to fundraise for various causes. "I hate running - but I thought



Holly and Sophie

it would be a good challenge for me - and why not raise funds for MS while I'm doing it"

Holly set up an appeal on the 'Give a little' site and set herself a target of \$300. Through a combination of social media/clients/family she raised the sum of \$1,355. "I was pretty happy with that result"

As for the run itself? "Yeah, it was great - perfect conditions - raining and cool. I ran with my sister Sophie, and we had fun".

Holly is no stranger to fundraising for MS. Born in Sheffield, England she had moved to Nairobi with her mother who had been diagnosed with MS. While there Hollie had taken part in a cycle safari riding 800 km across Kenya to raise funds for research into MS.

"It's a funny thing this MS' says Holly "Since mum has been in Kenya she has suffered four relapses, and they were all during a stressful period when she went through a tough divorce from my father. But since then she has had no relapses for 12 years."

Ian Maxwell

The 2015 Fine Homes Tour



Tracey, Karen, Janet, Liz

For those of you who are not familiar with the event, The Fine Homes Tour is a wonderful Waikato fundraiser.

Every two years, 10 of Hamilton's finest homes are opened to viewing by the public. Established in 2003 by Pamela Townsend, Christine Couch and Jane Hargood the event has gone from strength to strength.

The last event took place on the 13th November and we were very fortunate to have been selected as one of the recipients.

With every tour a different 10 homes are chosen and

show cased with up to 1600 people viewing each of these homes.

The staff, along with Helen, our former colleague, were very fortunate to enjoy the day out too. We saw some lovely homes, some modern, some older properties which had been beautifully renovated, all of which were amazing.

Organising this event is no small task! It is only possible with the generosity of the wonderful home owners who allow so many people to take a look around their pristine homes; the fine homes committee members who devote many hours to organising and ensuring the day is a success; the many volunteers who assist on the day and their wonderful sponsors who ensure that all funds raised can be donated to local charities.

Our Trustees were invited along to a presentation at the end of November where we received a cheque for \$27,000.

We would like to extend our sincere thanks and appreciation to all those who were involved in this event and for your support of our organisation.

Cruisin' to Kawhia 2015



At the Juke Box Diner

Anytime one gets up at 4.30am you know you're going to be in for a long day. And so it was on 1 November, 2015 – Kawhia Cruise day – my wife and I leapt out of bed ready to start what was going to be a long day. At 4.30am?? Well.... there was the small matter of the Rugby World Cup to get through first! (note to self – chat to Adam about checking what else might be on the day you set for the big event).

6.30 am ... World Cup done and dusted – whoo – hoo – take that Aussie – “four more years”...and all that. Time for a shower, brekkie and a relaxing coffee and off down to the `Juke Box Diner' to join the muscle car enthusiasts



Geoff, Ian and Jill

and supporters.

We are among the later of the arrivals, but a quick look around at the number of coffee swilling attendees wearing silver fern emblazoned black shirts, confirms we weren't the only early risers. Time for a quick wander around, checking out the beautiful cars on display, catching up with old acquaintances...sharing a bit of cup final banter, and of course ... another cup of coffee. I find Adam (Muir – event organiser) and get introduced to Geoff who will be our driver on the trip out. Geoff, who is acting as chief photographer for the day, will be driving Adam's pride and joy – a 1969 Chevrolet Mailbu

with the Carlos (Adam's nick name from his rallying days after world champion Carlos Sains) number plate. Adam was in control of his late wife Shelley's 1958 Chevrolet Apache christened `Elmo`.

Introductions complete I climb into the passenger seat and we're off. As we head off down Rifle Range road I come to the unnerving realization that yes – this is a left hand drive and I am facing the oncoming traffic with no driving wheel to take evasive action. Major road works at Temple View allows all the participants to regroup in true convoy style and gives the local inhabitants a great chance to get a close up look of the cars on display. Once through the road works it is a quick jaunt through to Pirongia where we head off to a back street and assemble on both sides of the road for a quick catch up and chat.

Geoff pulls in behind a beautiful red & white 1961 Corvette. On disembarking (with a tad difficulty) I have



Clare and the Corvette

a chat to Clare – owner of the Corvette. Turns out she had wanted to own a Corvette since she was 11 years old and first saw one on the television show `Route 66`. A couple of years ago she was fulfilling a `bucket list` trip to America cruising Route 66 with a bunch of other enthusiasts. One day in Illinois the wives went off shoe shopping and the blokes went to a car museum. Clare went with the blokes. "In the museum there it was – the car I had always wanted. I cheekily asked if it was for sale and it was! Apparently a `good ole boy` local farmer had purchased the vehicle new for his wife but she didn't like it. The car had sat unused in a garage for years and wasn't discovered until the farmer had died. Some local car enthusiasts restored the car to its original state and donated it to the museum. They were after cash to acquire some desired vehicles and negotiations started on the spot. At tea that night the other wives were showing off their shoes and I was showing off my car!"

Time to move and Geoff is off first – he is after a photo at the Kawhia turn-off. As Geoff waits for his target we count the cars as they pass by and get a tally of just

over 100 before we re-join the convoy. After a couple of stops to fix the hood which popped open (including an encounter with a friendly farmer who obliged while driving past on his quad bike) it was off to Oparau for another scheduled stop. By the time we arrived it was hard to find a parking spot. We were in more luck than a family out for a Sunday drive. They stopped in for a quick ice cream and had to join the back of a very long line of motor enthusiasts getting their coffee fix. The stop at Oparau offered another chance to mix and mingle and to allow Richard a chance to exercise his lungs and auction off some motoring paraphernalia.

All done and dusted it was off to Kawhia. The convoy easily filled up the Reserve and spilled out onto the streets surrounding. Judging of cars was undertaken and prizes given out. The band `Shot Gun` are on hand to play some old favourites. Jill and I retire to Annie's Café to chill for a bit. Meanwhile the hot sun, early start and laid back music were having an effect on the gathering



Registrations

as the day drifted into a lazy Sunday afternoon. Still hard at work manning a barbeque and selling drinks however were Ray and Joanne Young and daughter Danielle. While Adam is still very much the face of the Kawhia Cruise, Ray and Joanne have taken over much of the organising and `nuts & bolts` of the event ensuring all the i's are dotted and t's crossed. As the Cruise faithful start to drift away and head home Jill and I cadge a ride home with MS staffer Janet and hubby Steve in a 2000 something Kia Rio – doing our best not to be recognised.

In the three years the event has been running the biggest change has been in who is attending. Year 1 nearly everyone was friends and family of Adam and Shelley. This year there were a lot of enthusiasts who had seen the event advertised and come along. Adam at one point noted with pleasure that he didn't know half of the people attending.

The cruise raised a total of \$2,202.

This Year's Cruise - 6th November. See you then!

Ian Maxwell

Rachel's Many Steps for MS



Rachel Kirkbride from Christchurch is walking the Te Araroa Trail – a 3,000 km journey from Cape Reinga to Bluff – to raise awareness of MS and gather a bit of money (for funding research) along the way. I caught up with her 800km (and 1 month walking) into her journey in the plush surroundings of the Life Unlimited building. She is glowing, after a quick make over and shower courtesy of Liz, and decked out in a new bright orange `Kawhia Cruise' `T' shirt.

“So...that accent, where are you from” says I. “Liverpool” says she. “Ahh.. you’re `scouse’ then?” says I. “No I’m not – don’t call me that – I’m from the Everton side. Anyway, what are you – a Manchester United fan (spits on floor – figuratively)” says she. “No – Spurs actually” says I. “God, worse...” says she...

Off to a good start thinks I...any way here we go...

Rachel has been in New Zealand, living in Christchurch, for 20 years. So the obvious question is `Why the walk, and why now’?

“Two reasons. First, I’ve recently turned 49 – the same age my brother, Ian, was when he died from complications of MS (pneumonia). God...he was a good looking bugger – lived life to the full. For a time he lived in Russia and loved it – and those long-legged Russian girls!” Ian was working as a forestry worker in England when his hands started shaking and he couldn’t let go of his chainsaw. He was eventually diagnosed with Secondary Progressive MS. “When I went to see him he was in a wheel chair and undertaking steroid treatment. Soon after he was confined to bed – he was only in his mid-thirties – and he stayed that way for 15 years until he died. So I’m doing this walk to honour his memory and to raise awareness of a disease that no-one seems to know much about.”

“Secondly – I’ve just finished rebuilding my house in New Brighton – it got wrecked in the 2011 earthquake. It’s been a real mission – five years of negativity. I just wanted to get out of Christchurch for a while. I

wanted to see a bit of New Zealand and get some positivity back into my life. So I got someone in to rent my place and off I went. This walk is the perfect fit for both aims.”

Before starting the walk Rachel contacted all the MS offices around the country giving them a rough itinerary and pointing them to her `blog’ site so they could follow her progress. She requested help with provisions and accommodation along the way.

Rachel started her walk on October 21st and found the first few days the hardest. “The walk along Ninety Mile Beach was tough. It was blowing a gale and pouring with rain. I had to camp rough those first few nights. You know - these things can be quite tough at times – you really have to have a good reason to do it. I have come across a lot of other `mad’ people also doing the trek – some for fun – others like me raising money. Everyone is very supportive. A lot of the campsite owners along the way offer free camping if you are doing the Trail.”

On reaching Auckland Rachel stayed with one of the local MS support people and was invited along to an MS fundraiser to speak. (Sir) Bob Jones was also speaking at the function. “One of the local MS staff approached Bob and suggested that I needed a `Go-Pro’ action camera to record my journey. He just said `send me the invoice’. He was a cool guy.”

Rachel has met a lot of lovely people along the way but a couple of 70 year olds stand out. “Kevin (from Newcastle) was sweet. I banged into him three times – I think he was stalking me” she laughs. “The last time – he was on a yellow `Ducati’. He suggested we find a place to stay the night and split the cost. I had to tell him that `I batted for the other team’. I hope I didn’t hurt his feelings.” The other `gentleman’ was a former Locomotive Driver from Hamilton. He had recently come back from a trip to Asia. “He now goes by the name `Cindy’ and is a burlesque dancer!”

We are interrupted by Karen – Rachel’s host for the night – who has to get going to do mother/farm hand things and needs to whisk Rachel away. Rachel mentions that both Karen and Liz have commented on how heavy her back pack is. “I look at you dragging that leg around and it’s probably no harder than that. Besides – I think of what our Ian went through – and this is nothing.”

Rachel was spending two nights in Hamilton before heading off – hoping to be in Wellington for Christmas Day. You can read her blog on <http://www.ms-trampnz.com/contact.html> to see how her journey is progressing.

Ian Maxwell

HD News



Ron and Erika



In November 2015 we hosted a HD Carer's Day. The day dawned bright and sunny and the venue, The Ol' Creamery in Ohaupo, was superb. Everyone arrived in great spirits after watching the final of the Rugby World Cup. Due to the clashing of dates for these events numbers were fewer than anticipated, but what transpired was an intimate group that gelled and connected well together. The focus of the day was not only to hear from two inspiring speakers that offered some great advice but also to offer the opportunity to connect with others who are walking a similar path, reducing the feeling of isolation in the carer's journey.

In the morning Ron Dick, Neuropsychologist, spoke of how the Huntington's brain changes and the impacts this can create. Open discussion was had regarding individual concerns and some strategies offered to manage behaviours that are challenging. Lunch

was enjoyed in the sunny courtyard and then in the afternoon Erica Weerekoona, Counsellor, spoke about loss and grief and the importance of self care. Through using mindfulness techniques Erica gave a sense of permission that it is okay to feel a range of feelings from frustration and anger to sadness and grief.

The day ended with afternoon tea under the pergola where reflections of the day were shared along with a gift bag for all. Feedback was overwhelmingly positive with everyone hoping for another day to be arranged in the future. This will definitely be on the cards for 2016!

In the planning stages at present is a social catch up for HD Carer's, so that they can rekindle their connections in a social setting and make new connections with those who couldn't attend in November.

Tracey Larsen

ME/CFS & FM Updates

Welcome to 2016! Already the year is shaping up to be busy with some exciting speakers being considered for our monthly meetings.

The last quarter of last year proved to be a busy time. In September we had Lisa Crow from the Sleep Well clinic advise us on the benefits and impacts of good and poor sleep and provide some great strategies on how to develop good sleep hygiene practices.

October's group meeting topic was on Stress Management covering what stress is and how it impacts the body. I took the group through some simple and easy management techniques such as deep breathing and a mindfulness activity.

The November meeting resulted in an open group discussion about pacing, resting, planning and stress management. One group member also shared a brief

outline of her approach to health as she has been successful in achieving a sense of recovery in the last 6 or so months. This was very inspiring to all who attended.

Our Christmas lunch this year was hosted by The Hamilton Workingmen's Club in Frankton. The menu consisted of a cooked lunch which catered for gluten and dairy free dietary concerns and proved to be very cost effective. Everyone who attended enjoyed the lunch and seemed to appreciate the quite peaceful atmosphere the club provided.

I am looking forward to seeing what unfolds for 2016 - I will be arranging another visit from Dr Vallings and ME/CFS & FM awareness week in May are two events to keep an eye out for.

Tracey Larsen

MSNZ welcomes PHARMAC's decision to fund two new first-line treatments for relapsing - remitting forms of Multiple Sclerosis.

The Multiple Sclerosis Society of New Zealand (MSNZ) welcomes PHARMAC's decision to fund two new first-line treatments for relapsing-remitting forms of MS.

The new treatments: dimethyl fumarate (Tecfidera) supplied by Biogen NZ and teriflunomide (Aubagio) supplied by Sanofi-Aventis NZ will be funded in the community and in DHB hospitals, subject to the same restrictions that apply to natalizumab (Tysabri) and fingolimod (Gilenya).

"There are approximately 4,000 people with multiple sclerosis in New Zealand," says MSNZ spokesman Neil Woodhams. "This announcement is a really positive step forward for them."

Access to the two new treatments comes on the back of access to Tysabri and Gilenya last year and extended access to older injectable treatments.

"This time last year PHARMAC extended the access criteria for Tysabri and Gilenya and we are seeing how that change is making a difference in people's lives. We know from figures that PHARMAC has provided that 471 people with MS have been approved to receive Tysabri or Gilenya within the first 12 months of funding. We hope that the impact of access to Tecfidera and Aubagio will be just as positive."

MSNZ made several other requests as part of its submission to PHARMAC in October, particularly regarding the overall entry and exit criteria for MS treatments.

"We are still concerned the overall entry and exit criteria are too tight," says Mr Woodhams. "There needs to be some flexibility. New Zealand is the only country to have such stringent exit criteria under the Expanded Disability Status Scale (EDSS).

"Some people diagnosed with relapsing-remitting MS unfortunately experience a high number of relapses that produce disability in the long or medium term. In some instances a person may have attacks of the spinal cord that

leave them with permanent disability in their movement. As per the EDSS scale this will put them over point that they can enter into treatment. However their poor recovery does not mean that they have a more progressive form of MS but are still considered relapsing-remitting.

Mr Woodhams says that there needs to be scope in the entry criteria to treat those with relapsing-remitting MS who have experienced severe relapses to the point that their recovery does not go below the currently defined entry mark.

"We remain concerned for patients who have had their first demyelinating episode (CIS) with proven MRI activity and demonstrable symptoms of MS and who would benefit from early treatment still have to wait for a significant relapse. We understand from PHARMAC's feedback this would require a larger review in relation to budgets and risk/benefit analysis. Our concern is to ensure a person with MS does not have to experience disability from a relapse before they can access treatment.

"These treatments may still have an extremely positive effect on other factors affecting the person's MS. Significant disability in one area should not clinically make someone ineligible."

In terms of eligibility, MSNZ is seeking reassurance from PHARMAC that these applications will still receive fair consideration.

"We would also value some clarification about whether applications would be accepted. PHARMAC have advised that applications can be made if circumstances are outside the criteria, however we would like more reassurance these will be fully considered."

About MSNZ:

For more information about MSNZ please email info@msnz.org.nz or call 0800 MS LINE (67 54 63).

Media release (8 December 2015) by the MS Society of New Zealand

ANNUAL GENERAL MEETING

The AGM will take place on Wednesday 23rd March at 6.00 pm in the hall of St Peters Cathedral, 51 Victoria St. Guest speaker Neil Woodhams will talk on the role of MSNZ in advocacy and research. Neil sits on the consumer advisory committee for Pharmac and the MS Research Trust. He is also Vice President of MSNZ and Chairperson of MS Auckland.

This will be followed by a light supper; financial members will be eligible to vote at the AGM. To reserve a seat please contact Janet on 8344740 or email janet@mswaikato.org.nz.

NOTICE BOARD

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.

Website

Our website has been re-developed, take a look at our new one at www.mswaikato.org.nz

The Michael Ford / MS Waikato Charity Golf Tournament

Our annual golf tournament is taking place on Friday 4th March, this will be played on the Lochiel course at the Riverside Golf Club. Registration and morning tea 10.00am, shotgun start at 11.00am.

Register by 25 February and early bird registration is only \$35, after this date it will be \$40. The tournament is a fun day out, includes morning tea, sausage sizzle and a drink during the game with great prizes to be won, it is open to players of all abilities.

If you are interested in playing, sponsoring, or volunteering at the tournament please contact Janet on 07 834 4740 or email janet@mswaikato.org.nz

Show your ability Expo

The 2016 'Show your Ability' (disability equipment) expo will be held at the Claudelands Event Centre on Wednesday 24th February.

The event runs from 9 - 3, with free entry.

On display will be all kinds of equipment for younger and older disabled people and older persons care equipment

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.

The Entertainment Book

MS Waikato will be selling the Waikato/ Bay of Plenty Entertainment books again this year, this is now available in both digital and hard copy. For only \$60 you receive thousands of dollars worth of vouchers in our region. MS Waikato will receive \$12 from each book sold. The book will be available from the 31st March with pre-sales being available from the end of February. A sample book will be available in the office to view.

Totara Springs

We will be holding a camp at Totara Springs from the 4th - 6th March. Cost is \$60 per adult and \$40 per child 14 yrs and under, max of \$200 per family.

The camp is subsidised and places are limited, please contact Liz on 07 834 4741 or liz@mswaikato.org.nz

A day of fun at Hamilton Zoo

Dinsdale Lions in conjunction with Hamilton Zoo and Friends of Hamilton Zoo will be holding their 20th annual zoo day on Sunday 20th March from 11.00 - 3.00 pm.

Entry is free for people with disabilities and their immediate family/caregiver.

Transport within the city boundaries can be provided if this is registered by the 4th March.

For more information contact Roger Bell on 027 440 0370.

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

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MSWT EVENTS CALENDAR

MARCH 2016

SUN	MON	TUE	WED	THU	FRI	SAT
		1 MS Support Group Te Awamutu 10am Dawn till Dusk	2 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	3	4 The Michael Ford Golf Tournament Totara Springs	5 Totara Springs
6 Totara Springs	7 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	8	9 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	10 ME/CFS & FM Methodist Church Bader St, Melville 10.30am	11	12
13	14 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	15	16 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	17 MS Support Group Mometawa, Te Aroha 10am	18	19
20	21 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	22	23 MS Exercise Class 10.30am–11.30am AGM St Peters Cathedral 6.00pm	24	25	26
27	28 Easter Monday	29	30 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	31		

APRIL 2016

SUN	MON	TUE	WED	THU	FRI	SAT
					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 ANZAC Day	26	27 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	28	29	30

MAY 2016

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

Please Cut Here

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