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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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*ManuScript is brought to you by:*



## The Michael Ford Golf Tournament 2014

Welcome to, what was generally agreed to be the 15th Michael Ford Golf Tournament.

It was yet another beautiful, hot, hot, hot day in the Waikato as golfers mooched about at the Lochiel Golf Club waiting for the day's celebs to arrive. We did – Bruce and I – almost late, and got to our positions at the fourth green almost before the first balls started landing. As I approached the green at a rapid limp I noticed two balls already nestling on the green, a third in the bunker and the fourth ... making one of those scary 'incoming' noises that 22mm shells make, lands just to my right and rolls between my feet. "It's alright Bruce" I shout "I'm fine". Bruce, blissfully unaware of the action is busy checking out his play lunch that Mrs Bruce had packed for him.

The first group of golfers appear greenside and make short work of chipping and putting out. A promising start – could be in for a busy day. Alas, that promise was not to eventuate as a succession of golfers splayed their shots left, right and short. No one could blame the conditions – there wasn't a hint of a breeze and it's not like they couldn't see the Green – it was the only green bit on parched fairway.

With a lack of action Bruce and I busied ourselves swapping play lunch – Bruce offers a slightly passed 'use by date' piece of short bread for a 'just out of the oven, still warm' piece of chocolate brownie and a slightly bruised bargain bin apple for a bunch of home-grown, insecticide free grapes! Bruce stares suspiciously at his plastic wrapped supermarket bought sandwiches that Liz has just given us and is busy calculating the re-sell value when a ball hits the edge of the bunker guarding the green and shoots off to the side. Bruce, ever helpful, dashes off to



**Luke McKenzie and Chairperson Mark Etheridge**



**Preparing for the game**

pinpoint where the ball ends up and is still fossicking in the undergrowth when the ball's owner turns up. After 10 minutes of fruitless searching the chaps playing companion points out a ball some 50 yards away which turns out to be the one they are looking for! Bruce skulks back to his chair and engages Janet in earnest conversation. The girls leave us a fully fuelled golf cart and enough food and water to see out a week long siege.

A long period of inactivity sees me delving into my bag for the 'keep Bruce amused' kit. This year's selection comprises a 90's quiz selection and a book of 30 minute crossword puzzles. Ten minutes is long enough to deduce that the ninety's were not a good decade for Bruce so we try the crosswords. It becomes obvious that Bruce is distracted and keeps looking past the fourth tee to the approaching golfers. "I think I will go and get us some sausages" declares Bruce and heads off into the distance in the golf cart.

From my vantage point I observe Bruce criss-crossing the golf course. Bruce returns with 'well done' sausages and tales of a 'newbie' volunteer helping Helen out on the Barbie. "Well" I declare "They have to start somewhere". It is hoped Aaron's experience was not too distressing and he is up to returning next year and one day maybe graduating to our lofty heights!

It is not until the last foursome tee off that we see any real action as a ball comes to rest in the outer circle. Bruce runs onto the green to confirm the ball's status dropping sun glasses, phone, keys and sandwich wrappings in his wake. As the foursome approach, Bruce rushes, the first to reach the green requesting a photo opportunity. Unfortunately, he is the gentleman who has put his ball in the bunker and takes a further 3 shots to land on the green. He is suitably miffed when Bruce no longer wants his photo and is instead ingratiating himself with the chap putting for a birdie.

Back in the clubhouse we get a chance to have a cool beer and watch the 'burglers' (including Dodgy Dave from the Parkinson's exercise group) pick up their trophies. Best Stableford was awarded to Luke McKenzie. Great to see Jo (Mike's wife) there for the formalities!

Thanks to the girls for their efforts and of course to all the following sponsors:

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- Lugtons - Terry Ryan

**Ian Maxwell**

This year's tournament raised a total of \$3,933!  
Thank you also to our wonderful volunteers and the players for making it a successful day.



**Getting in some practice shots**



**Jeremy running the gambling hole**



**Aaron and Helen**



**Ian and Bruce**

## ME / CFS Update

The cooler autumn temperatures are a blessing for those with ME/CFS and FM whose symptoms worsen with the summer heat because of disturbed thermo regulation. We have still been having some very warm days for this time of the year however.

It's been another busy couple of months, but we are very fortunate to have our new staff member, Tracey Larsen, on board getting started in her new role. The plan at this stage is for Tracey to ease in to spending some of her time helping with the ME/CFS work load which has greatly increased since I started in this position. Tracey has a counselling degree, which is a very useful skill to bring to the role, and I'm sure she will fit in very well.

Kylie Phillips, from Phillips Family Chiropractic was our guest speaker at our February Support Group meeting. Her topic was about stress and the affect it has on our bodies. She told us that there are six types of stress and explained the various types and that stress can be good or bad. She went on to explain the functions of the para sympathetic and sympathetic nervous system and what happens when we are stressed. Kylie gave us a questionnaire to determine where our stress levels were at. This produced the interesting result of nearly everyone being in the red zone graph, i.e. highly stressed!

She finished by discussing some helpful stress management strategies.

Our speaker for March was Michelle Peat from the Consumer Health Service, who gave a very interesting talk about her role. She told us that they are an independent trust contracted by the Midland District Health Board to ensure people using a health or disability service have protection under the Code of Rights. They can therefore seek help from a free and independent health and disability advocate to help resolve concerns and complaints. This may also result in changes that will benefit others.



**Michelle Peat**



**Kylie Phillips**

**Helen Maseyk**  
**Client Services Coordinator**  
**ME/CFS**

## Meet Tracey Larsen



In a cunning cost saving move MS Waikato has replaced one Tracy for another Tracey – just think of the cost savings on things like badges, cards etc. – not to mention retraining Monica to be nice to yet another name. Unfortunately due to an appalling lack of due diligence we ended up with a Tracey with an ‘e’. Never mind – at least

Mon won't have to be rewired –for now.

Meet Tracey Larsen the latest addition to the MS Waikato team. Tracey comes to us having recently graduated with a degree in Social Sciences. Tracey's last job was in a bank – “It just wasn't me” she says. “I've always

wanted to work as a counsellor – and although I am not employed as one here my counselling skills are valuable and will be well utilised”.

Tracey worked as a Case Manager for ACC for about 10 years during the 90's before giving it up to start a family and help out on the farm. She returned to the work force at the bank but didn't really settle. “I really enjoyed the client contact I had at ACC and I was inspired to become a counsellor”. So, she quit her job at the bank and attended Wintec full time for three years. “I'm really excited to be here and can't wait to get into the job”. Tracey's lack of a medical background has meant her first week has been a crash course in reading medical literature. “It's been full-on, but I've learnt so much already” she enthuses.

Tracy will be working 20 hours a week initially and will be looking after the Huntington clients and helping out Liz and Helen where needed.

**Ian Maxwell**

## The 2014 BDO Bike Ride

Not for the faint hearted this challenge takes cyclists from Wellington to Pukekohe over the course of 7 days. With the MS Society of New Zealand named as official recipients from the ride we took the opportunity to be involved with the event too.

Commencing in Wellington on Sunday 9th February the riders face a gruelling challenge cycling through the heartland of New Zealand, riding a total of over 700 km's. Day 6 saw the riders reach our region when they finished for the day in Te Awamutu. The final day of the event - Saturday 15th February, the cyclists were

to start from Hamilton's BDO office on Victoria Street. Helen and I went along to support the event and raise awareness of MS Waikato.

The event encourages both individuals and corporate teams to participate and is now into its 6th year. Riding for MS NZ was Auckland's Pam Smith, joining her were a total of 160 riders. The event raised a total of \$20,297 for the MS Society of New Zealand.

Thank you to BDO for your support.

**Janet Buckingham**



**Janet and Helen**



**The BDO team**



**Bernard Lamusse and Pam Smith**



**The race begins**

## Liz and Tracey's Graduation

MS Waikato would like to congratulate Liz and Tracey on successfully completing their Bachelor of Social Science degrees.

Liz is now a qualified Social Worker and Tracey a Counsellor.



## Dr Allbon – I presume?

Remember back when you were diagnosed with MS? How did you feel? A little confused. You may have been told “You’ve got MS – you’ll probably be in a wheelchair in less than 12 months – heck you may even go blind!” You would have wanted to know a little bit more about the disease, but you had no idea where to go for information or help? Well back in 1998 Caroline Allbon was a nurse when she got diagnosed and she felt a bit like that. As a health professional she thought there had to be a better way for learning more about one’s confirmed diagnosis – transitioning from being a person without MS to now becoming a person with MS. More importantly whilst also adjusting to one’s new life were her thoughts of how a confirmed diagnosis such as this was communicated.

The idea to do something about that process kicked around in her head while she carried on with her career, married, had children – all while battling the debilitating disease we share. When I last interviewed Caroline (2007) she had just been named the Person with MS of the Year. The demands of nursing shift work were now placing too much strain on her health and she decided to look at other ways to still retain all her nursing and teaching skills. She looked at contracting herself to Schools of Nursing as a contract marker and hence evolved her own research company – Research Connect Ltd. At the time she was also working as a board member for MSWT with research students from the University of Waikato on a project for MS Waikato. Over the years (2007-2008) Caroline had had numerous discussions with members of the health industry and academics about the process of the journey for patients from diagnosis to living with a chronic disease. It had been mentioned that she should do a PhD using this subject as a topic and had also been encouraged to take her research further.

In 2008 Caroline decided now was the time and contacted people at the University of Waikato – Department of Strategic Human Resources – Waikato Management School (whom she had met during her research project) and put the idea to them. Universities don’t just let anyone do a PhD – they have a reputation to protect – so you have to sell the idea to them and produce an original piece of work that will make a useful contribution to knowledge. Caroline enrolled at the University in 2008 and for the next six months was engaged in writing up her full research proposal. Although she met the first criteria of having at least 3 degrees (Bachelor of Nursing; Bachelor of Social Sciences with Honours; Master Social Sciences Honours) Caroline still had to present a CV and a full bio. In late 2008 her full research proposal was approved. Caroline was now a fully enrolled PhD Doctoral candidate – whilst studying full time she still has a chronic disease and a family remember!

It was Caroline’s ambition to complete her PhD in 5 years. As she was no longer undertaking contractual marking work this aim was significantly aided with the help of gaining 3 scholarships to meet the costs associated with full time doctoral study.

To gain a PhD you have to do a bit of writing. Your completed work can’t exceed 100,000 words and must include: a Title; Hypothesis; Aim; Methodology; Results; Discussion; Conclusion and Recommendations. Every thesis needs a title and Caroline’s was a doozy - The being in somebody – an Auto ethnographic account of Being, and Becoming, in the world with MS’. How to approach the subject and where to start

was an initial problem but it was suggested to Caroline that she use her own diagnosis as a starting point – to look at how it was communicated to her and take it from there – her mission - “to make the invisible, visible.”

Following a lecture she gave at the Liverpool School of Management – Liverpool University UK, in 2009 – Caroline’s early stages of a ‘seed of an idea’ for research, teaching and doing auto ethnography were very well received. This idea now became the platform for a paper that was accepted for publication in the inaugural first edition of the Journal of Organisational Ethnography in 2012.

To cut a long, and challenging, story short – she has been and gone and done it. Her supervisors were impressed, her markers (1 international, 1 local) gave her the thumbs up and The University is right chuffed. Caroline, or should I say, Dr Caroline, got her PhD and funny hat and graduated in October 2013. Her thesis – all 242 pages of it is beautifully bound and proudly sits on the shelves of the University of Waikato’s Library. It is also available in digital format as well which has been submitted to research commons at The University of Waikato’s library, Waikato District Health Board and Wintec Library. To access the ‘big book’ on line here is the link:

<http://researchcommons.waikato.ac.nz/handle/10289/7967>

Caroline is justly proud of her work and is confident its recommendations will make a difference within the health industry.

And the future? Caroline has resurrected her research company ‘Research Connect’ and aims to outsource her research skills to the health management and health education industry for research and evaluation of clinical health projects. Go well girl!

**Ian Maxwell**



## Breakthrough programme halts Huntington's progression

**BEING sociable and exercising your mind and body can significantly slow down the progression of Huntington's disease for those who are beginning to show symptoms according to a world- first study by Western Australian researchers.**

The disorder, which affects muscle coordination and causes progressive mental and physical deterioration is a type of dementia, related to Alzheimer's disease, and it is caused by a mutation in either one of an individual's two copies of a gene called Huntingtin.

Currently researchers are trying to identify treatments to stop its progression and improve quality of life, while the search for a cure continues. One promising study found the disease's progression was significantly slowed down in mice given a physical and mental exercise programme – this strategy forming the basis of a pilot study in WA.

The Huntington's Exercise Research Optimisation study recruited 20 patients in early to mid stages of Huntington's disease to find out if a prolonged programme of mental and physical rehabilitation would positively impact on features of the disease.

The programme ran over 23 months and included gym-based exercises, home- based physical exercises and occupational therapy. The pilot had remarkable results with participants deteriorating at a 50 per cent slower rate than a group who did not do the programme – they also had noticeable improvements in body composition, muscular strength and perceptions of mental health. In addition, participants showed mental improvement, which reached statistical significance for some aspects of cognitive function.

Researchers concluded the pilot study shows it's possible to considerably impact on the progression of Huntington's disease in a cohort of individuals at early-mid stages of the disease.

But they say larger studies are warranted to more clearly explain the programme's benefits.

Following the pilot's success, researchers are recruiting for a new study with participants yet to be diagnosed as symptomatic. This study will offer participants an ongoing multidisciplinary rehabilitation programme as an adjunct to their normal pharmaceutical regime.

"Aerobic exercise is known to increase some chemicals in the brain – one called brain-derived neurotropic factor, which stimulates neurogenesis and we have to do quite a bit of exercise in this programme to switch that on." "There were very few other studies in humans and we were the world's first to undertake such an all encompassing programme in people and the aim is to improve their quality of life for a longer period of time, so they can maintain their independence."

Source: ScienceNetwork Western Australia. [newshd.net/journals/4494/breakthrough-program-halts-huntingtons-progression/admin](http://newshd.net/journals/4494/breakthrough-program-halts-huntingtons-progression/admin)

## Book Review

### Recovering from Multiple Sclerosis.

**Real life stories of hope and inspiration.**

A wonderful, positive enlightening and hopeful read about real people living with MS. All of the people in the book have taken on the lifestyle changes suggested by Professor George Jelinek in his books "Taking Control of MS" and "Overcoming MS". There are 12 short stories, all unique and all fascinating. Of special interest is the story "Finding authenticity" which is Megan Swan's story (pg. 134). Some of you may remember Megan; she featured in Issue 12 of Manuscript with a story about her experiences at Mana Retreat in 2009. It is wonderful to read how, 4 years later she continues to thrive, living life to the full and most importantly she is enjoying life. The final chapter talks about finding hope and is very encouraging. All of George Jelinek's books are available from the MS Waikato library.



# NOTICE BOARD

## National Huntington's Conference

11 – 12 September

This will take place at Perth's University of Western Australia, UWA Club.

The full programme and further information will be available shortly from [www.huntingtonswa.org.au](http://www.huntingtonswa.org.au)

## Vitamin D

If you are interested in purchasing a quantity of Vitamin D please contact

Carole Stark on 07 827 7695 or email [peterandcarole@xtra.co.nz](mailto:peterandcarole@xtra.co.nz)

## World MS Day

Thursday 29th May

World MS Day is the internationally recognised day for MS Awareness.

MS Waikato will be having stalls around the Waikato, if you would like to volunteer to assist please ring Janet on 07 834 4740.

## \*\* Education Evening \*\*

An MS education evening with neurologist Jan Schepel will be held on Monday 19th May, 6.45 pm at The Link (corner of River Road and Te Aroha Street), this will be followed by a light supper.

If you would like to attend could you please advise us by Wednesday 14th May, phone 834 4740 or email [mswanaikato@mswanaikato.org.nz](mailto:mswanaikato@mswanaikato.org.nz).

## ME/CFS and Fibromyalgia Day

Thursday 15th May

Awareness stalls will be in Hamilton on this day, if you would like to volunteer to assist please ring Helen on 07 834 4742.

## The Wellbeing Waikato Show

The Wellbeing Waikato show is now integrated with the Waikato Show and will take place at the Claudelands Event Centre on Friday 11 – Sunday 13 April.

We do welcome any feedback you may have on the newsletter.

## Computer Help at Hamilton City Libraries

If you are new to computers and battling to get a grip on it Hamilton City Libraries may be able to help. They have established a new Computer Mentor service to assist customers who need help with their personal technology.

This service is currently available at Dinsdale, Glenview and Garden Place Libraries, it is a free service and a mentor can be booked for up to two hours.

For more information visit [www.hamiltonlibraries.co.nz](http://www.hamiltonlibraries.co.nz) or contact Lisa Pritchard on 07 838 6410 or Jeff Neems on 07 838 6509.

## Subscriptions

2014 subscriptions are now due; these are \$35 or \$17.50 if you hold a Community Services Card. A subscription form is enclosed for those who have not already paid.

Thank you for your ongoing support.

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South Waikato District Council • The Lido • Rehabilitation Welfare Trust



# MSWT EVENTS CALENDAR

## MAY 2014

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton <b>MS Support Group</b> Te Awamutu 10am, Dusk Till Dawn	6	7 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	8 <b>ME/CFS Support Group</b> Methodist Church Bader St, Melville 10.30am	9	10
11	12 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	13	14 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	15 <b>ME / CFS &amp; Fibromyalgia Day</b> <b>MS Support Group</b> Mometewa Morrinsville, 10am	16	17
18	19 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	20	21 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	22	23	24
25	26 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	27 <b>ME (Chronic Fatigue)</b> Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	28 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	29 <b>World MS Day Collections</b>	30	31

## JUNE 2014

SUN	MON	TUE	WED	THU	FRI	SAT
1	2 <i>Queen's Birthday</i>	3	4 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	5	6	7
8	9 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton <b>MS Support Group</b> Te Awamutu 10am, Dusk Till Dawn	10	11 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	12 <b>ME/CFS Support Group</b> Methodist Church Bader St, Melville 10.30am	13	14
15	16 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	17	18 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	19 <b>MS Support Group</b> Mometewa Matamata, 10am	20	21
22	23 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	24 <b>ME (Chronic Fatigue)</b> Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	25 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26	27	28
29	30 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton					

Please Cut Here

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