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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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Andrew Hunt puts faith in stem cell treatment

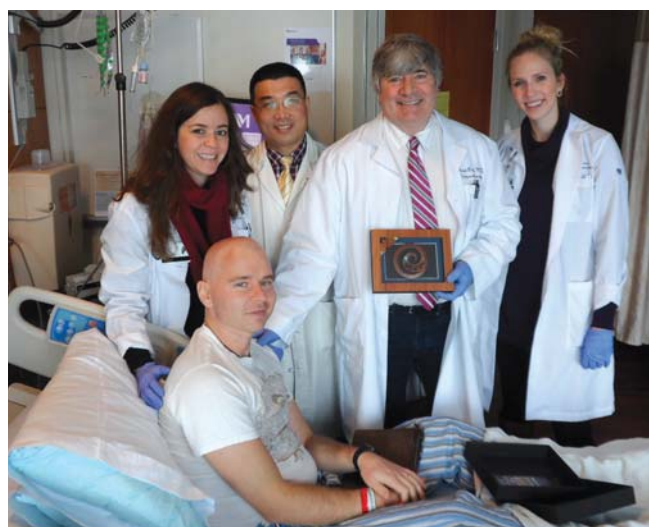
Andrew Hunt is a man of faith – and it took a leap of faith for him to leave his Cambridge home and travel to America to try an, as yet, unapproved treatment to cure him of MS. Well Andrew (35) has ‘been there and done it’ - and now it’s wait and see what happens.

Andrew was diagnosed with relapsing/remitting MS in 2006. For a while he participated in a drug trial (BG00012 TECFIDERA) which was going ok but he and his wife Marie, whom he married in 2007, wanted to start a family. This was not possible while on the trial so he left the programme. Fast forward to 2014 and Andrew (now the father of two bouncing boys) is struggling with his leg movement and balance. In September he had to give up his job as an Anaesthetic Technician at Southern Cross Hospital.

“I kept bumping into things and tripping over cables etc” he says.

Now home with his sons (Marie had returned to work) he was becoming increasingly frustrated watching other fathers running around playing with their children – a simple task he was unable to do.

It was about then Andrew and Marie saw a ‘60 Minutes’ programme about an Australian woman, Kristy Cruise, an MS patient who had travelled to Russia and undergone a radical treatment – and was now seemingly cured. The treatment was HSCT (Hematopoietic Stem Cell Transplantation) and at the time the procedure (not yet FDA approved) was being carried out in many hospitals around the world – including Chicago (USA), Israel, Germany, Sydney, Russia, and India.



Andrew and the Medical Team

The treatment is also now being carried out in Singapore, Mexico and the Philippines.

Andrew made enquiries to three hospitals. From the replies he received he had the most confidence in Chicago.

“They wanted to know more about my background. They had criteria I had to meet – they just appeared to be more professional”.

The cost, however, was prohibitive and the couple decided it was beyond them. But his mother turned up and said ‘we can do this’ and Andrew’s family started organising fund-raising events. Their church also became involved with the fund-raising and after about two months the funds were available.

Andrew began correspondence in earnest with Dr Burt at North Western Memorial Hospital in Chicago.

“He was carrying out his own HSCT trial at the time and was prepared to take me on as a non-trial patient providing I met the criteria” says Andrew. “In my first consultation with Dr Burt, he said following the tests that they had conducted, I was on the verge of going into secondary progressive MS and then he



said to me 'that if anything is going to help you – then this is it'. I was relieved that I hadn't left it any longer".

What does HSCT do? Well to put it very basically – the blood stem cells are removed, the white blood cells get zapped, the stem cells are replaced and the white blood cells are regrown – in effect creating a new immune system – without MS. Although trials have been carried out the treatment does not yet have FDA (Food & Drug Administration) approval. To gain approval – it must be shown that the procedure provides reasonable safety and effectiveness.

Andrew left New Zealand on 31 December 2014 with his father and set up camp at a hotel in Chicago. The first week there he underwent a series of tests (MRI etc) to make sure he met the required criteria for the procedure. Once confirmed, he underwent a series of chemotherapy sessions. The first dose of chemo was called 'Chemo Mobilisation'. This is to move the stem cells from Andrew's bone marrow into his blood, ready for harvesting.

A week later Andrew had a fever and his MS symptoms went into overdrive and he had to be treated with steroids and antibiotics. When his system returned to normal Andrew had his blood stem cells removed. He then spent a week back in the hotel, and then back to hospital for four sessions of chemotherapy to destroy the white blood cells.

The immune system is then reset and the stem cells that were harvested are used to grow the new immune system. This day now becomes the immune system's 'birthday'. Andrew then had three infusions of red blood cells. Then it was a waiting game for the white blood cells to reproduce to the correct level.

During this period Andrew suffered a few days of irregular heart rate. "It was pretty horrible – and a bit scary". But Andrew was never really worried. "Dr Burt was very reassuring and said that it would pass shortly".

The day came when the white blood cell level had returned to normal and Andrew was allowed to leave the hospital. After a few days he had one last blood test and he was off home – arriving back in New Zealand on 10 March.

He continues to have regular blood tests with his local GP and the results are sent back to Chicago. Andrew continues to keep in touch with the other patients who were part of Dr Burt's trial.

So, it's mid July as I talk to Andrew and how does he feel? "Well, I feel stronger, my leg movement is a lot easier – I managed a 1.5km walk on the treadmill the other day. It's early days yet. I'm giving myself a year to rest my body and then I will hopefully get back to work" Andrew says. "It's a two year recovery and it's best to get this treatment done as early as possible before there is substantial damage in your body from MS. It's great to see my body improving."

All through this process Andrew kept a blog. You can read this by searching 'HSCT For Hope' on Facebook

If you want to find out more about HSCT you can go to http://www.stemcellimmunotherapy.com/who_burt.htm1.

Ian Maxwell

The information in this article is presented with the intention of informing only and in no way reflects any opinion of MS Waikato Trust about the safety or effectiveness of the treatment.



Holly's MS Run

On Sunday 15th November Holly Pass will be running Hamilton's 'Round the Bridges'. In Holly's words she is 'not an MS sufferer but an MS fighter'.

Holly is not just running the race, she is also fundraising for us too, please check out Holly's page on give a little <http://givealittle.co.nz/project/hollymsrun> and consider supporting her too.

Rachel's Te Araroa Challenge

Beginning 21st October 2015 Rachel Kirkbride will be taking on the tremendous challenge of tramping the Te Araroa Trail, a 3000km journey down the length of New Zealand.

Why? To raise awareness for MS in memory of her brother Ian who passed away with progressive MS that left him wheelchair and bed bound for 15 years.

The journey will take Rachel 5 months, and she will be walking through the Waikato late November. She really needs all the support she can get so if you are able to help Rachel either by making food drops to her along the way, show a friendly face or if you would like to join her for part of the trek we really encourage you to make contact. Rachel will be able to advise you when she expects to be in your area and how you can help her with this challenge.

If you would like to support Rachel please let us know, or you can contact Rachel directly via her website: <http://www.ms-trampnz.com/contact.html>.



MS Nurses Australasia Conference



Liz and Karen

Karen Thomas, neurological clinical nurse specialist (CNS) and myself have worked closely together for a number of years because we both believe that robust collaboration would mean better care and safer outcomes for our clients.

When Karen approached me earlier this year with the idea that we could present our model of care to our colleagues at the Australia and New Zealand MS nurses conference I was quick to accept the challenge. Together we produced a conference poster titled “How collaboration and communication = a better coordinated client service”.

We began by discussing the history and significance of our partnership, went on to define our individual roles and where we worked together. We then discussed how

and why our model works, and looked at the benefits to Karen as CNS, myself as client services manager and most importantly to our MS clients. We were pleased and not surprised to identify that the greatest benefit is to the MS clients. Next was the identification of a pathway of care for MS clients to access help and support when needed. We finished by discussing potential issues with the model and a brief look to the future in the ever-changing environment of health care.

Over the course of developing the poster I personally found it extremely helpful to formalise what we had been doing and to analyse it in depth. Karen and I meet weekly to discuss client issues. We do genuinely believe that because we both work in different environments (Karen in the hospital and me mostly in the community), and come from different perspectives (Karen has a more medical model while I have a more social model), we are able to offer a more holistic service when we work together. I also appreciate the safe oversight from the neurologists at the hospital. We have tried to create a model which is sustainable into the future and does not rely on individuals but is maintainable between Waikato Hospital and MS Waikato Trust.

Liz Hogan

So far so good

It's hard to believe that it's been 10 years since I started working at MS Waikato, first as a field worker for the MS and HD clients, then as the client services manager working closely with our MS clients and overseeing services to all our client groups. I could never have imagined that I would have been so inspired and humbled as I had the privilege of walking alongside some amazing people as they negotiate the often difficult path when life changes for them.

I have also been lucky to work with such good people along the way, Janet who has been here a little longer than me and Monica who (it seems) has been here forever! Currently we have wonderful staff with Tracey and Karen and some really good people on the board of Trustees; but it is the clients and their families who inspire me the most.

Liz Hogan

Remember this, it's back again – Totara Springs!

We will be holding another camp at Totara Springs from the 4th – 6th March 2016. If you have not been to a camp before it is a wonderful opportunity to meet other members and their families, share experiences and participate in a wide range of activities. The many activities will include archery, top town games, flying fox and the hot pool; all activities are in a supportive environment with the opportunity to participate in things you may not have experienced for a while.

Accommodation is in lodges with all meals included. The cost is \$60 per adult and \$40 per child with a maximum of \$200 per family. The camp is subsidised and bookings are essential, if you would like to book a place contact Liz on 07 834 4741 or email liz@mswaikato.org.nz.



St John Caring Caller

Caring Caller is a service that St John provides for people who live alone or feel a bit lonely. Volunteers phone clients regularly to check that everything is ok. This free service is fully funded by donations.

Partners and friends pass on. Family members don't always live close by. Neighbours aren't always interested in getting to know you. And if you're unable to get out or you're unwell, it can be hard to meet people.

Just having someone ask about your day can make all the difference to how you're feeling. It's even better if that someone shares your interests, like gardening, reading or sport. Looking forward to a good conversation can really brighten up the day.

St John's free Caring Caller service connects people who need a friend with people who have time to listen and chat. While it's not a helpline in any way, a Caring Caller can also notify the right people – St John – if their chat friend isn't well or doesn't answer.

The people who become callers are community-minded individuals who understand the need for care and want to make a difference to someone's life. They have the time to make regular calls and build a friendship. They

can also provide reminders that help with everyday life, like remembering to take medication or put the rubbish out. There's no money involved – Caring Callers are volunteer phone friends, doing a service because their hearts are in the right place.

Would you like a Caring Caller?

If you're living alone, or you're housebound due to illness or disability, you can contact St John about getting a Caring Caller. They try to pair you up with a volunteer whose personality and interests match yours. Caring Callers might not yet be available in your area, but always ask them – they love a challenge. Unlike some services, Caring Caller is free of charge.

Enquire now on 0800 000 606

Do you know someone who needs a Caring Caller?

People who are lonely don't always recognise that they need a friend, so it's up to others to get the ball rolling. They welcome referrals from community-minded people who know of someone who could use a friend.

Enquire now on 0800 000 606

ME/CFS & FM Updates

In August Dr Vallings shared with the ME/CFS Education Support Group the latest research efforts and findings presented at the 2015 10th Annual 'Invest in ME' conference in London. A good turnout of clients and public came to hear her speak and the feedback was very positive.

Apparently there is much ongoing research focusing on food and nutrition and bowel bacteria as an imbalance of bacteria impacts the immune system. The bowel also influences the production of Serotonin – the 'feel good' endorphin. It has been shown that for some ME/CFS suffers there is a poor release of serotonin. An American gastroenterologist has also been researching stomach bugs and has found an unusual virus in a large percentage of ME/CFS sufferers who experience severe gastric symptoms.

Swedish researchers are looking at proteins in the cerebral spinal fluid. So far some definite differences between the proteins of healthy individuals and ME/CFS patients have been found. It is hoped that a bio marker may be established as a result of this study.

Research regarding intolerance to visual glare (light sensitivity) has resulted in interesting findings. Impairment with pupil contraction has been noted. Usually the pupil will contract in bright

light but researchers have noticed that the eye will contract and then dilate again instead of staying contracted, which can cause post exertion malaise of the eyes and hence difficulty with eye movement, multi-tasking and driving.

An exercise physiologist has suggested that Yoga and Tai chi is recommended as an ideal form of exercise. Building up core strength is most important as core muscles hold the body in good posture. They also suggest that a good rule to follow is a 1 in 3 plan - 3 times the amount of rest for the amount of exercise. For example 30 seconds exercise should be followed by 90 seconds rest. 30 minutes' walk = 1½ hours of rest.

A DVD recording of Dr Vallings talk is available to loan. Please contact me on 834 4745 if you would like to borrow this.

Tracey Larsen



HD News

The work of neurobiologist Dr Melanie Cheung (Ngāti Rangitihī) from the University's Centre for Brain Research is right at the forefront of an international thrust towards enhancing the power of the human brain. Melanie is leading a team of scientists and clinicians who are seeking to prevent the advance of symptoms in people with the gene for Huntington's disease.

And they are doing this in a totally new way: not through a process of drug discovery but through an intensive programme of carefully-crafted brain plasticity-based cognitive exercises specifically chosen to address the symptoms of Huntington's disease.

Says Melanie "There's an adage that says: 'Neurons that fire together wire together'. If you can get a group of neurons [the nerve cells in the brain that process and transmit information through electrical and chemical messages] to consistently fire together, then you can change a pathway. This process, called brain plasticity, is essentially what our research is about. "So what we're trying to do is harness the brain's natural processes to change the way it functions and stimulate its own pharmaceutical stores in a way that helps it fix itself. "The types of improvements can be very specific because you can design particular inputs to engage the parts of the brain that need to be strengthened."

Melanie selected 33 sets of exercises (from among around 200 sets available) that were likely to be effective in addressing the early symptoms of Huntington's disease: the exercises train attention, working memory, processing speed, sequencing, temporal processing, emotional recognition and mental flexibility. Using these selected sets of exercises, Melanie and her team have developed a treatment requiring 30 minutes of computer-based "brain training" five times a week over 40 weeks. The exercises are designed to train the participants specifically in those capacities that are impaired in Huntington's disease.

Forty of these people are doing the selected brain plasticity-based exercises and a control group of 40 are doing a more general cognitive training. Half of the participants are asymptomatic carriers of the Huntington's disease gene while the other half are members of the same families but are not carrying the gene.

The researchers are not sure if brain plasticity-based training will be able to cure the disease completely.



However, Melanie says that they hope to cause a delay in the symptoms and enhance the brain power of all groups in the study.

The work cuts across the lines between disciplines, as Melanie explains. The participants undergo MRI (magnetic resonance imaging) scans to allow examination of the structure and function of their brains; neuropsychological assessments to measure attention, memory, sequencing, emotional recognition, mental speed and flexibility and verbal fluency; neuropsychiatric assessments to measure the progression of such mental states as anxiety, depression, apathy, irritability (all common among those with Huntington's disease); and measurement of olfaction (since Huntington's disease, like all neurological diseases, affects the patients' ability to recognise smells).

"We are also measuring serum BDNF, a marker for neuroplasticity in people's blood; [using] the Unified Huntington's Disease Rating Scale, which assesses the clinical features and course of HD," she adds.

"What we're hoping to see is that the dysfunctional pathways become corrected. Even after three weeks of training [already completed at the time of the interview] there are some signs of a lift in mood and improved memory among participants."

Richard Faull describes this work as "remarkable" because it is the first research in the world to focus on the effects of cognitive exercises on the progression of Huntington's disease. This project has been funded by Health Research Council and Fullbright New Zealand.

Article written by Judy Wilford (Abridged), Information sourced from <http://www.ingeniomagazine.com/powering-the-brain>



TPPA implications for PHARMAC raise serious concerns for people with MS

The Multiple Sclerosis Society of New Zealand (MSNZ) is extremely concerned by the potential implications of the proposed Trans-Pacific Partnership Agreement for people with multiple sclerosis.

“The TPPA could undermine PHARMAC’s buying power and its right to choose the most appropriate and cost-effective drugs. It could also impede its ability to negotiate confidentially to gain the best price. This could have devastating consequences for people with MS and their families,” said Multiple Sclerosis New Zealand President Malcolm Rickerby.

“Many people with MS are from low income households or are beneficiaries, due to an inability to work caused by their MS symptoms. Many of their partners and family members are also on a low wage or are carers. This makes them extremely vulnerable to any increases in prescription charges, which we see as a very likely consequence of the TPPA’s impact on PHARMAC.”

Mr Rickerby said that if New Zealand agrees to a situation where pharmaceutical patents are extended from five to eight years, as speculated by some commentators, this will have a serious knock-on effect and constrain PHARMAC from funding new drugs in the future.

“New Zealanders will pay higher costs for patented drugs for longer unless the Government increases PHARMAC’s budget to offset that change to patents. What we are seeking is a firm commitment from the Government that the extended patent protection resulting from participation in the TPPA will not limit or constrain access to the next generation of MS drugs.

PHARMAC funding for the latest generation MS drugs is already seven years behind Australia due to Government funding constraints, said Mr Rickerby. “Only the latest MS drugs are shown to have clinical efficacy. In the case of MS treatment, there is no scope for substituting generics.”

Since PHARMAC negotiated the best price for bringing two important new MS treatments to New Zealand last year there has been a strong demand for the new treatments, he said.

“The number of people applying for those treatments has already exceeded the number PHARMAC expected to be approved for treatment for the whole of 2015.”

Media release (30 July 2015)
The MS Society of New Zealand

Thank you for your support:

Waikato Mobility Scooters

We would like to acknowledge the support of Mark Bacchus of Waikato Mobility Scooters, we know that Mark has gone out of his way to provide amazing support to some of our clients.



If you require servicing or advice for your mobility scooter or wheelchair please do consider calling Mark on 07 858 2246 or email heartway@orcon.net.nz.

MS Awareness Week

Thank you so much to those of you who gave up your time to assist with our awareness stall in Chartwell.

Also, a huge thank you to the BNZ for supporting us during MS Awareness Week. Staff in Tokoroa and Otorohanga organised awareness stalls, the BNZ had collection pots in all branches and regional Manager Mat Bowling assisted and advised in the office for the day.

Important Telephone Numbers

Your Own Doctor	Lifeline - Outside Hamilton	0800 838 0719
Anglesea Clinic..... 07 858 0800	Mental Health Waikato Hospital	07 838 3752
In an Emergency..... 111	NZ Drug Foundation	0800 787 797
Medical Helpline (Advice)..... 0800 611 116	Police - Central Station	07 858 6200
Mental Health Helpline..... 0800 505 050	Tenancy Service.....	0800 836 262
Citizens Advice Bureau..... 0800 367 222	Victim Support Helpline.....	0800 838 0719
Dept of Work & Income	Crisis Team (CAT Team)	0800 50 50 50
Electricity Complaints	Depression Helpline	0800 111 757
Inland Revenue (IRD)..... 0800 227 773	Suicide Prevention Helpline	0508 828 865
Lifeline - Hamilton..... 0800 543 354	Health Line.....	0800 811 116

The Trustees and staff would like to wish you a safe and happy Christmas and a prosperous New Year!



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.

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. Thank you for your support.

Christmas Lunch

We would love to have you join us for Christmas lunch. This will be a 2 course buffet at the Hamilton Workingmen's Club. The lunch will be subsidised by the Trust for individuals who have paid their subs.

Date - **Thursday 3rd December**

Time - **To arrive from 12.00,**
lunch will be served at 12.30

Cost - \$10 for financial members,
\$20 for non-financial members

Bookings essential by 30th November,
phone 07 834 4740 or email janet@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. The tournament is a fun day out and 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

Exercise Classes

The last exercise class before Christmas will be on Wednesday 23rd December, the classes will re-start Monday 11th January.

Our website is currently being re-developed, keep a look out for the new one at www.mswaikato.org.nz

The Fine Homes Tour

MS Waikato are fortunate to have been selected as recipients from Hamilton's 2015 Fine Homes Tour.

The event enables you to view 10 of Hamilton's finest homes and is taking place on Friday 13th November, tickets are \$70 and can be purchased from www.finehometour.co.nz

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, it sleeps 4 to 5 people and is specifically designed to accommodate a wheelchair. Being only 200 metres from the Hauraki Rail Trail it 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 to us. If you are interested please view their website www.8076.co.nz. To make a booking ring Jo on 07 862 4943 or email Jo_banb8076@yahoo.co.nz, and mention MS Waikato (don't use the online booking calendar as they won't know the booking is for MS people).

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

Christmas Closure

The office will close on Wednesday 23rd December and re-open on Monday 25th January.

Thanks to our Sponsors and Supporters

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The Sutherland Self Help Trust • The Gallagher Charitable Trust • Rotary Club of Cambridge • Waikato Lyceum Charitable Trust
MediSun Ltd • Waikato Mobility Scooters





MSWT EVENTS CALENDAR

DECEMBER 2015

SUN	MON	TUE	WED	THU	FRI	SAT
		1	2 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	3 MS & HD Christmas Lunch Hamilton Workingmen's Club 12pm	4	5
6	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 Christmas Lunch Hamilton Workingmen's Club 12pm Mometewa Christmas Lunch	11	12
13	14 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	15 MS Support Group Christmas Lunch Te Awamutu RSA Club 11am	16 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	17	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 Anytime Fitness 56 Tristram St Hamilton	24	25 Christmas Day	26 Boxing Day
27	28	29	30	31	** MS OFFICE CLOSED **	
** MS OFFICE CLOSED **						

JANUARY 2016

SUN	MON	TUE	WED	THU	FRI	SAT
31					1 New Year's Day	2
3	4	5	6	7	8	9
** MS OFFICE CLOSED **						
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	15	16
** MS OFFICE CLOSED **						
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	22	23
** MS OFFICE CLOSED **						
24	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS OFFICE RE-OPENS	26	27 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28	29	30

FEBRUARY 2016

SUN	MON	TUE	WED	THU	FRI	SAT
	1 Auckland Anniversary	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 Waitangi Day	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 Mometewa Morrinsville 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				

Please Cut Here

MS Waikato Trust, Life Unlimited Building, 20 Palmerston Street, PO Box 146, Hamilton 3240

Tel 07-834 4740, Email mswaikato@mswaikato.org.nz, Website www.mswaikato.org.nz

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