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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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Win, win, win



Shelley and her mum, Mavis

It was a case of win, win, win when Whitianga resident Shelley Armour decided to throw herself out of a plane on Mother's Day in May.

Shelley's parents Mick and Mavis Anslow were out from England visiting her and Mother's Day happened to fall during their visit. Shelley had always wanted to skydive and it was a bucket list item of her mum's.

She decided it would be a great chance to do the Mother's Day pressie and put a tick on both of their bucket lists in one go and booked in a jump for her and her mum. A Mother's Day they would not forget.

As it was the first time parachuting for both of them. Shelley thought she would mark the occasion by turning it into a fundraiser for MS. 'My sister did a skydive in England last year raising money for MS UK so I thought I could do that - a bit of sibling rivalry I suppose'

Initially Shelley targeted her and her husband's work mates and family for donations but eventually spread her

attention to other businesses in town. 'I was really thrilled with the positive support I got from the community' she says. The final total collected was \$2,002.

As for the jump - well it was 'fantastic'. 'The only downer was that we had to do the dive in Mt Maunganui as it is not offered in Whitianga,' We took this opportunity to explore the Bay of Plenty for a few days after the jump'. The jump itself was a tandem dive with Shelley, Mavis and their instructors being taken up to 10,000 feet. 'It was the first time I've been in a small plane. Gosh, I looked down and we seemed to be so high. I asked if we were high enough yet and we still had a few thousand feet to go!

Shelley says the funny thing was she wasn't a bit nervous about the jump 'And then I got a bit nervous because I wasn't nervous!' 'When we jumped we went head first and went into freefall for 30-40 seconds. It was great - a real adrenaline rush - and I can't wait to do it again.

Ian Maxwell

Our Trustees

Over the past few months there have been some changes to our board as we welcomed some new Trustees.

Graham Haines who has led our organisation for several years has now stepped aside as Chairperson. Graham has provided us with great support and leadership and is still continuing as a Trustee.



**New MS Waikato Chairperson
Leanne Milligan**

We are very pleased to welcome Leanne Milligan who recently joined our Board and was elected Chairperson at our June meeting. Leanne is the Chief Financial Officer at Waitomo Petroleum Ltd in Hamilton so it's a quick trip past the lake and over the hill before she is at the MS Offices.

Leanne also serves as the Company Secretary for Waitomo Petroleum. In her spare time Leanne is an active member of Altrusa International, serving on the International Board of Directors which means several trips to the US for meetings a year. She is a member of her local club in Te Awamutu.

Altrusa International is a network of service clubs that focus on improving their local communities through leadership and service and she has served on the governing boards at a local, national and international level since 1994. In the past she has also served on

the Te Awamutu Museum trust board and Kainga Aroha Community House Board. Leanne has a long time commitments to making a difference in the community and feels that through her coming work for MS Waikato she can continue to do this. Leanne is excited to be a member of such a great board and is looking forward to working with the dedicated team at MS Waikato to help ensure the very best service can be provided for clients.

We are also pleased to welcome as Trustees Chris Luoni, Erin Burke and Karin Thomas. Chris is a company director and business advisor and a long time supporter of our organisation, sponsoring our annual Golf Tournament for the past 16 years. Erin and Karin both practice law, each with their own practice.



New Trustees Chris Luoni, Erin Burke and Karin Thomas

Our Trustees are all professional individuals who give their time voluntarily. Originating from a variety of different backgrounds, they bring a wealth of knowledge and experience, which ensures our organisation, is led by a strong and robust board.

Our board are now – Leanne Milligan, Graham Haines, Mark Etheridge, Caroline Allbon, Frankie Letford, Clare Simcock, Graham Derrick, Chris Luoni, Karin Thomas and Erin Burke.

Client Survey

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

For those of you who have provided us with an email address this will be sent to you via email with a link to complete this online. If we don't have your email address a survey and envelope for return will be included with this newsletter. Please complete the survey and return to us by 29th August.

If you have any questions, difficulty in accessing the survey, or do not receive a copy, please contact Janet:

(07) 834 4740 or janet@mswaikato.org.nz .

Thank you for your support.

MS Education Evening

It was wet and miserable night but many braved the elements and filled the room to listen to neurologist Jan Schepel's informative talk on diet, exercise, medication and meditation. The information Jan share offered advice for improving general wellbeing thus assisting with helping to manage and cope with MS.

A healthy nutritious diet is an important tool for living well. This includes less saturated fat. Avoid aspartame in diet drinks as this can irritate the bladder, this is not good for those who have sensitive bladders! High fibre in the diet can help those who experience constipation. High salt intake can weaken the blood brain barrier which is associated with relapses and T2 lesions. Being overweight can increase fatigue and cardio vascular problems and worsen MS prognosis. Obesity increases the risk of inflammation because adipose tissue can synthesis and regulate inflammation.

A healthy diet, activity and less stress is important for a healthy gut. A healthy gut has good bacteria-butyrate which have an anti inflammatory effect on the rest of the body, so important for MS.

Jan discussed the importance of exercise for all types of MS. It helps with mobility, muscle strength, improves fitness, and reduces fatigue. It has great cognitive benefits and improves mood. It can have an anti inflammatory effect and gives neuro-protection to the neurons.

Jan outlined the new oral drugs that are now available.

The benefits of including meditation into daily life are that it helps with coping with stress, can reduce the chances of depression. It's simple to do, costs nothing and is beneficial for the brain.

The talk was finished with the participation of all in a Kirtan Kriya meditation practice, which improves memory, reduces stress enhances brain blood flow and improves brain chemistry. The room was filled with the chanting of Sa Ta Ra Ma. The evening finished with supper and a chat. An entertaining and informative evening, thank you Jan!

Karen Bird

MS and Exercise

The majority of people with MS do not exercise; some fear that it will worsen their symptoms. However, recent research has shown that regular exercise can have positive, not negative, effects on MS. Exercise has neurological benefits – release of beneficial hormones, enhancing the anti-inflammatory mechanism, slowing the disease progression, remyelination.

There are 6 core exercise principles for MS:

- FUN
- HIGH INTENSITY
- FREQUENCY
- INTERVALS
- CHALLENGING
- SPECIFICITY

High Intensity drives neuroprotection and intervals help manage your symptoms. Remember if there is no challenge, there will be no change! The exercise should get you out of

breath, even for a short period and be done 3-4 times a week. There are many different ways to exercise; choose the one(s) you enjoy..... and have fun!

Hydrotherapy is one of the best, contrary to popular belief, despite the heat; the water will cool your body. To help control heat during any exercise, have a bottle of iced water to sip on.

You can expect increased symptoms and fatigue during exercise but this should only last 20 minutes to 2 hours. To achieve the best results you should consult with someone who knows the specifics about MS and exercise.

People with MS need to exercise now.

Margaret Thomson

- Personal Trainer and leader of MS/Parkinson's gym group

The MS Waikato Exercise Class

The exercise classes are available for all our members. They are a great way to improve your health and wellbeing. Taking place each Monday and Wednesday morning at Anytime Fitness on Tristram St, the class is lead by Margaret Thomson.

For those who have paid their subscriptions the cost is only \$2 per session, otherwise this is charged at \$5 a session.

If you would like to attend, registration is essential so please contact Liz, Karen or Tracey and they will arrange to meet you for your first session.

New members are always welcome.

World MS Day

World MS Day is a global awareness day for Multiple Sclerosis. It is an opportunity to raise awareness and to bring people together. Taking place this year on the 25th May MS Waikato organised several stalls during this week in Hamilton, Cambridge and Morrinsville. The purpose of the stalls is not just to raise funds but also to raise awareness and understanding of Multiple Sclerosis. The stalls raised a total of \$1,110; we would like to thank the many wonderful volunteers who gave up their time to assist us with this.



Paul and Adam



Holly and Fran

ME/CFS Updates

It has been a busy few months with exciting guest speakers at the ME/CFS & FM support Group Meetings.

In May Counsellor Erica Weerekoon spoke to us about how grief and loss can be experienced when facing a chronic illness and how accepting change requires coming to terms with a new reality. Christine Jessup from the Unirec spoke to us in June about the importance of exercise and how to approach exercise when suffering ME/CFS and/or Fibromyalgia. July saw Medical Herbalist Sue Mitchell presenting to the group a holistic approach to health via herbal medicine which requires a personalised detailed assessment. As she described many herbs and their beneficial properties to varying symptoms she also stressed the importance of understanding how and when to take such remedies as herbs can interact and react with medication.

The August Support Group meeting will be open to the public as Dr Ros Vallings our NZ specialist will be presenting a brief overview of key research findings that were presented at the London Invest in ME conference in June. She will also be discussing how the compromised immune system plays a major role in ME/CFS.

May the 12th was also ME/CFS awareness day. Volunteers held a stall at Westfields Chartwell and an information display could also be viewed at the Hamilton City Library in Garden Place. Information packs were sent out to all secondary schools in the greater Waikato region from which several responses have been received. Awareness of ME/CFS and Fibromyalgia is

slowly increasing as I am continuing to receive regular inquiries for help. Many of these have found MS Waikato via the internet and our new website.

Tracey Larsen



Volunteers Helen and Maree at the stall held in Westfield Chartwell



MS Research

Four “risk” genes associated with multiple sclerosis discovered

Scientists of the Technical University of Munich (TUM) and the Max Planck Institute of Psychiatry have identified four new risk genes that are altered in German patients with multiple sclerosis (MS). The results point to a possible involvement of cellular mechanisms in the development of the condition, through which environmental influences affect gene regulation. The research project was supported by the German Competence Network Multiple Sclerosis (KKNMS).

The newly identified regions in the human genome associated with the disease improve our model of how MS develops. *“All four genes are important for regulatory processes within immune cells. Interestingly, they are linked to epigenetic mechanisms. These are bookmarks in the genome that are placed by environmental influences and control the expression of genes”*, explains Prof. Dr. Bernhard Hemmer, Director of the Clinic and Policlinic for Neurology at TUM's Klinikum rechts der Isar and Spokesman of the Executive Board of the KKNMS.

Epigenetic signals mark DNA sequences in human cells and are critical for regulating which of the approximately 20,000 genes inside a cell get activated. These signals are programmed by environmental influences throughout a person's lifetime. One of the genes identified, named SHMT1, plays a central role in DNA methylation, one of the most important epigenetic regulatory mechanisms.

“Because the hereditary component in developing MS is limited, environmental factors strongly contribute to the disease. They can influence the activity of MS-relevant genes via epigenetic mechanisms. We have now discovered indicators for regulation of methylation being a potential interface where genetic and environmental MS risk factors interact”, said Prof. Dr. Bertram Müller-Myhsok, Research Group Leader Statistical Genetics at the Max Planck Institute of Psychiatry.

Not only did the scientists identify four new risk genes in the German population, but they also confirmed the existence of a dozen previously identified genes. In contrast to earlier studies, they took a new methodological approach: instead of examining a large number of international samples from different ethnic groups, the scientists focused on a single population of genetically homogeneous German patients. This allowed them to identify risk genes that had so far not been discovered in international studies. With just under 5,000 patients and a sample of over 10,000 healthy people, this is the largest genetic MS study carried out in a single country to date.

Source: Medical Xpress © Medical Xpress 2011 - 2016, Science X network (22/06/16)

Hippocampal inflammation linked to depression

Symptoms of multiple sclerosis have long been linked with the body's immune system, and immune response has also been linked to depression. Now researchers think it could be a shared pathological mechanism that leads to the increased rates of depressive symptoms in patients with multiple sclerosis.

A new study in Biological Psychiatry claims inflammation of the hippocampus, a region of the brain implicated in the genesis and maintenance of depression and in the pathology of multiple sclerosis, alters its function and contributes to symptoms of depression.

“This study elegantly links hippocampal inflammation to depression,” said Dr. John Krystal, Editor of Biological Psychiatry.

The research was a collaboration between King's College London, Imperial College London, and Imanova Center for Imaging Sciences. Led by senior authors Paul Matthews and Eugenii Rabiner, the research team combined two complementary brain imaging techniques to study the relationship between hippocampal immune response, functional connections, and depressive symptoms in 13 patients with multiple sclerosis and 22 healthy control subjects. Positron emission tomography (PET) allowed for quantification of activated microglia, a measure of immune response. Functional magnetic resonance imaging (fMRI) assessed the strength of hippocampal connections to an extensive network of brain regions involved in emotion.

First author Dr. Alessandro Colasanti, of King's College London, explained that PET imaging revealed immune activation in the hippocampus of patients with multiple sclerosis. *“We also discovered that more inflammation was associated to more severe symptoms of depression,”* said Colasanti.

Measurements of functional brain connections with fMRI during rest showed that immune activation in the hippocampus altered its connections with other brain regions. *“This study, combining two advanced complementary brain imaging methods, suggests that the inflammation of the hippocampus affects the brain function and causes depression,”* said Colasanti.

The findings suggest that hippocampal inflammation could be the contributing cause of high rates of depression in multiple sclerosis. The authors predict that an effective and targeted treatment of brain inflammation would help to restore brain function and protect against depression in multiple sclerosis.

Source: News-Medical.net Copyright 2000-2016 AZoM.com Limited (07/07/16)



**Tracey Larsen with
Neuropsychologist Ron Dick**

I was very fortunate to be able to attend the recent HD Conference held in Auckland in May. This was a busy weekend with lots of presentations showing New Zealand's very own research projects and their findings. It was also great to network with

other health professionals and field workers working with HD from around New Zealand.

Prof. Richard Faull opened the Conference stating that much of the research happening at the Centre for Brain Research in Auckland has shown that there are many varying differences between Huntington's brains and that no two brains are the same. Much research has also discovered how the different parts of the brain talk to each other and that the more stimulation the brain receives, the more brain cells will develop and grow to replace cell death.

PhD Student Samantha Murray shared the latest findings with the transgenic sheep model. Six years of data is now showing key pathological and behavioural findings. They can now see the early changes in sheep at 3, 6, 12 months and 3 years which is providing a greater understanding of disease progression. Samantha stated that protein aggregates are a key feature of HD and they have found that early in the disease progress aggregates reside outside of the cell but by 18 months to 3 years aggregates can be found inside the cell. By 5 years of disease progression the number of aggregates increased dramatically.

Gene silencing treatment is showing positive results. Treatment is injected directly into the striatum in the brain at 1 month. Early trials thus far are showing that the injection is safe; there is no cell death at the injection site; it is knocking down the gene and showing positive neurochemical changes, especially with the increase of P substance (regulates mood, anxiety and stress). The next hurdle is to work out how to successfully inject into the vein.

Assoc. Prof. Lynette Tippett spoke about neuro-imaging results of pre-symptomatic HD positive participants which have provided a greater understanding of early changes in the brain. She stated that when cell death occurs, it impacts the whole circuit and the ability for each part of the brain to talk to each other. Imaging can pick up areas of the cortex that are starting to thin which

correlate with subtle early behaviours associated with a reduction in mental flexibility such as having difficulty in shifting between tasks, multi-tasking, coping with change, difficulty with planning and organising and also behaviour and emotional regulation. The highlight of this research has been identifying the changes occurring in the back of the brain in the occipital region. Such changes account for visual processing difficulties such as recognising faces, spatial difficulties, responding to stimuli and the difficulties in recognising and reading body language. Another key finding was the big variables between age of onset patterns and progression with participants with the same CAG repeat.

Along side of this research is another project that has been looking at optical coherence and abnormalities. Ultra sound imaging of the optic nerve and retinal fibre has shown thinning in parts of the eye. As eye nerves are similar to brain nerves, loss of brain cells equates to loss of optical cells. Research involving 26 people has shown that speed of eye movement correlates with coordination. What this research offers is possibly a cheaper and easier option to track progress of disease through eye exams instead of costly MRI scans.

Details of other research presentations will be shared in future editions, but if you wish to know more please free to contact me.

Tracey Larsen

Genetic Testing for HD



We have recently purchased a copy of the DVD 'Do you really want to know?' which gives an in-depth look at the pros and cons of genetic testing for HD. It is worth viewing this DVD if you or a family member is considering testing.

To borrow this resource please phone Tracey on 07 8344745 or email tracey@mswaikato.org.nz

NOTICE BOARD

Presentation by Dr Ros Vallings

Presenting a brief overview of latest ME/CFS research findings

Thursday 11th August 2016 | 10.30am to 12.00
Melville Methodist Church
Cnr Bader St & Normandy Ave

To register, please phone Tracey on 8344745 or
email tracey@mswaikato.org.nz

All Welcome

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If you pay your subscriptions directly and have
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amend this now.

Aspire

Aspire course is coming up; the dates are
Saturday 10 September - Saturday 17 September
2016.

This is an 8 day low impact Outward Bound
course, designed for people aged 27+ with a
physical limitation, either from a health condition
or long term injury.

Scholarships are available for this course, full
information and sponsorship applications:
[www.outwardbound.co.nz/courses/course/
aspire/](http://www.outwardbound.co.nz/courses/course/aspire/)

Funding is also available through Work and
Income for anyone who is a client with them.

Donations and Bequests

Donations to MS Waikato can be made at anytime through
our website www.mswaikato.org.nz, please click the link
'to make a donation' and it will take you to the Spark
Foundations give a little website. Alternatively a direct link
to this site is through www.givealittle.co.nz/org/MSWT.

A bequest is a gift to charity and is made through your will,
please talk with a solicitor if you wish to make a bequest

Library Books

Please remember we maintain a library of books.
With books to support MS, HD, ME/CFS and
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.

St John's 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. If you wish to sign yourself up for this service
and receive a regular call from a Caring Caller phone
0800 780 780.

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

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
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Rehabilitation Welfare Trust • The Norah Howell Charitable Trust



MSWT EVENTS CALENDAR

SEPTEMBER 2016

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

OCTOBER 2016

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

NOVEMBER 2016

SUN	MON	TUE	WED	THU	FRI	SAT
		1 MS Support Group Te Awamutu Dawn till Dusk 10am	2 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	3	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 Support Group 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 Mometewa Matamata 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 Anytime Fitness 56 Tristram St Hamilton	24	25	26
27	28 Labour Day	29	30 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton			

Please Cut Here

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