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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:

**Life Unlimited Building
20 Palmerston Street
PO Box 146, Hamilton 3240**

**Ph: 07 834 4740
mswaikato@mswaikato.org.nz**

**Liz - 07 834 4741
Karen - 07 834 4742
Tracey - 07 834 4745
Janet - 07 834 4740**

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Mastering Maungatautari



Are you one of those types that likes going for a walk on a Sunday? Well, do you fancy going for a walk with a lovely ex-pat British lass to help her celebrate her 48th birthday and ... oh yeah... raise some money for a couple of good causes at the same time? If you are, read on – if you’re not read on anyway, there’s a chance for you to get out of this guilt free.

Sue Dela Rue lives in Karapiro where she has recently moved with her husband Patrick and daughter Gabrielle. Sue has MS – the relapsing/remitting version – and was diagnosed in 2006. “That was a big year” she says “My daughter was born in April and I was diagnosed in September”. At the time Sue was working full-time in Hamilton for a large corporate, Sue started suffering from blurred vision, fatigue and lack of balance. After the usual poking and prodding’s, referrals, tests and scans she was diagnosed with MS and initially put on the drug Copaxone. Unfortunately for Sue, she had a bad reaction to the Copaxone and was taken off the medication immediately. Sue was very reluctant to try any other drugs in fear of the

side effects and battled through the next three years without them. During that time her neurologist provided her with support, information and encouragement for other treatments until she eventually made the decision herself to trial Avonex, which she is still on today.

Fast forward to 2013 and Sue has another land mark year in her journey with MS. She is made redundant from her corporate job (a blessing in disguise that gave Sue the means to assess her life, take a rest and find a less stressful role). Sue wanted to get out of city working and back to the country and nature and was lucky enough to find a job as Administration Manager with the Maungatautari Ecological Island Trust. This is based on Pukeatua (30 minutes from Cambridge), the largest pest-proofed fenced reserve in the world and one of the few totally pest free reserves in New Zealand. Now in a less stressful job, on Avonex, Sue is now in a better space health wise but still feels a bit ‘blah’ in herself. “Then I read in the MS newsletter that the ‘Mastering Mountains Trust’ was offering

Mastering Maungatautari (continued)

scholarships to people who wanted to have a go at outdoor pursuits". From there Sue contacted Liz (Hogan) with a proposal to traverse Mt Maungatautari from north to south (something Sue had dreamed for years, however not being fit enough, and with her MS symptoms it seemed a dead end dream). The Mastering Mountains Trust awarded Sue with a grant to help her prepare for her venture (mostly covering costs of a personal trainer to get her fit for the climb), sponsorship from Macpac (for clothing/gear for the gym and mountain walk) and from MitoQ (for a year's supply of mitochondria-targeted antioxidants supplements). "It's been great – it's given me a goal – a challenge" she enthuses. "I'm a different person now – I've got something I can aim for and I feel I will achieve".

Sue was also sent some books by the grantor Mastering Mountains Trust on Overcoming MS, and since December after reading

the one of the books on the OMS (Overcoming Multiple Sclerosis diet), Sue has adopted the diet and along with the personal trainer once a week, walking every day and MitoQ supplements, Sue's health is improving making her feel happier and healthier and more confident to achieve even small goals she thought were out of reach.

So where do you, the reader, come in. Sue figured while she is doing this she may as well raise some funds and awareness for MS Waikato and the Maungatautari Ecological Island Trust and has set up a 'Give a little' page: givealittle.co.nz/search?q=mastering+maungatautari where people can sponsor her with funds raised being shared equally between the two charities. Sue welcomes anyone who would like to join her on the walk over the mountain – "The more the merrier". So here are the details:

The walk will take place on Sunday 24 September (Sue's

birthday) early morning (8.30am-9am – to be confirmed).

The mountain itself is 797 metres high but walking from north side (Hicks Road entrance, Cambridge) to the south side (Pukeatua) the journey will be approximately 12km with about a 500 metre rise. The walk should take 4-6 hours (the first 2 hours up-hill) and Sue reckons anyone with moderate fitness would be able to handle it (but some training is required).

We will be walking the new track which is graded and easier than the old track which can get steep / muddy and is recommended for experienced trampers.

If you are interested and want more details you can contact Liz Hogan at MS Waikato, email liz@mswaikato.org.nz or phone 07 834 4741. MS Waikato staff will be walking.

Ian Maxwell

Book Review

A Funny Thing Happened on the way to the Neurologist by *Shona Daube*

It can be very difficult to find humour in a health condition such as MS, without being condescending or schmaltzy. There is a fine line between seeing the humour in something and mocking it. In my view, Shona has achieved the former and, in doing so, has been able to manage her fears and concerns. This approach helps many of us. The book is a delight. The best word to describe it is winsome. To try to analyse it and make it a serious book about MS completely misses the point. The book will not appeal to some because of its quirky approach but I encourage you to read it and find out for yourself.

I have lived with MS as a carer, since 1993, and I can relate to many of the comments made by Shona. As my partner's condition has deteriorated, quite often our only fallback is humour. How else do you deal with unthinking idiots who believe she has MS because of

something she did in a previous life? If this is the case, we hope she had a ball at the time!

Shona light-heartedly deals with very personal issues such as image, dressing, fashion, pride, vomiting, public toilets and queuing, sensitivity to heat, breaking wind and fatigue - any and all of which can be real problems to PwMS on a daily basis.

For many of us, humour is very important, it keeps us going. The alternative of gloom and despondency is not attractive. This book certainly reflects Shona very well, she is individualistic with a great sense of humour and sense of fashion that grows on you. Whilst she is hugely independent she is able to draw on and rely on her immediate family support. This was very evident from the book launch and my personal observations.

Reviewed by William Pitt,

Treasurer and Acting President,

MS Wellington

The Michael Ford / MS Waikato Charity Golf Tournament

Our annual tournament took place on the 7th April. I was a little apprehensive as it approached; sandwiched between the remnants of cyclone Debbie and cyclone Cook we were fortunate to be blessed with a fine calm day!

Our tournament was originally established by one of our members – Michael Ford and has now been running now for 18 years on the Lochiel course; it is one of our major fundraisers.

With a field of 52 players, we played

a Stableford tournament and overall best Stableford was awarded to Brad Chibnall.

The event raised a total of \$6,163. All funds raised at the tournament will remain within our region to directly support our clients and their families.

Thank you to our generous sponsors and to the players without which the tournament would not be possible, and to our volunteers who gave up their time to assist on the day.

Janet Buckingham

Gold Sponsors

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Your Subscriptions and why we ask for them

Each year MS Waikato asks for subscriptions fees and we thought it might be helpful to explain why we ask for the subscription and how it is used.

Firstly to dispel a common myth, we are NOT a government funded organisation, only 14% of our funding comes from the Government. We are a small not for profit organisation which means that we have to mostly self fund to provide our services through fundraising and applying for Community Grants. MS Waikato has been serving the Waikato and Coromandel regions for 54 years, this has only been possible because of the generous support we have received from the community, however it is a big challenge to stay financially viable.

We have grown significantly in the last 10 years and now offer services to over 500 people (and their families/whanau) with Multiple Sclerosis, Huntington's Disease, Myalgic Encephalopathy/CFS and Fibromyalgia.

Our service includes working closely with people who are newly diagnosed, trying to get reliable, robust and up to date information together with symptom management strategies to them and their family. This is undertaken as soon as possible after a diagnosis and we continue with information whenever it is needed. We also work hard to support our people when they are unwell, we are often the link between them, the hospital and community services, offering suggestions and pathways for care and support. We send out a regular newsletter to our clients and other interested parties, support our clients at appointments with health providers and

other related organisations, like WINZ. We advocate for clients who are having issues, be it workplace, housing or something else.

We offer a professionally run exercise class and education sessions throughout the year. As a client you probably know about the obvious service we provide, what you may not know is that we also work hard in the wider community to educate other health professionals and the public. MS Waikato staff offer in-service education for resthomes and community living homes, we talk at education days for allied health professionals and are available to speak to interested community groups.

As you can see even if we are not directly involved with you on a one to one at any given time, we are available to support you when you need that support. Our area is the greater Waikato, where we do home visits as needed from Whitianga to Taumaranui.

Every little bit helps and we would appreciate it so much if you are able to pay the annual subscription of \$40, or \$20 if you have a community services card. We are happy to discuss quarterly payments if that would help you or if you really feel it is too much we would be grateful for a donation. Payments can be deposited directly to our bank account, 02 0316 0488196 000, remembering to include your name and that payment is for subscriptions.

Thank you to those of you who have paid subscriptions this year, a subs notice is included if this payment has not been received yet.

Five ways to stay healthy during the change of seasons

Many people stress with the change of seasons, particularly with the coming of autumn and the return of school and transitioning of schedules. Autumn is known as a time of decreased immunity. Increased colds and flus and increased stress due to the coming of the cold season combine with the impending holiday season for a stressful time period. But this doesn't have to be if we follow some simple techniques to stay healthy and whole during the fall season.

Breathe fresh air as often as you can. Just because it is getting a little chillier doesn't mean that you have to come inside until spring comes around again. Breathe into your belly. This is diaphragmatic breathing, and it improves our immunity, detoxifies us and exercises our internal organs.

Stay hydrated. Autumn is the beginning of the dry season and many people will become dehydrated because they feel it is not hot enough to be drinking water. Increased water intake can improve back pain from doing autumn yard work, the immune system, and

help prevent many acute and chronic illnesses.

Eat well and eat in season, and local as much as possible. Autumn provides us with root vegetables, fresh fruit, pumpkins and squashes which contain beta carotene, vitamin C, and many other nutrients that can improve our immune function.

Continue to move, even though the cooler season is coming. Maintain or start your exercise routine to improve immune function and to counter the blues and mood swings which can come about with the decrease of light.

Get plenty of rest for restoration and rejuvenation. As the light decreases, embrace it as a time to look inward and improve yourself for your work and your mission. Prepare yourself for the time change and the decreased light by getting to bed earlier.

Les Moore, ND, DHANP, LAc., is a naturopath, homeopath and licensed acupuncturist practicing in Pittsford. As promoted by Exult.

MS Research

Scientists discover how to alter the immune system and reverse paralysis in mice.

Scientists have made another advance in finding a new potential treatment of MS by discovering a new way to alter the immune system without using chemotherapy.

In a mouse study a group of scientists have managed to tame the erratic immune response that triggers the condition and reverse paralysis.

“The problem with current immunotherapies is that they aren’t specific,” says Christopher Jewell, Ph.D. “They act broadly, compromising the entire immune system and putting the patient’s health at risk, rather than focusing on only those immune system cells doing the damage.”

By considering how the immune system works, Jewell’s team at the University of Maryland set their sights on the lymph nodes as a possible target for creating a specific immune response. In autoimmune disease, a body-roaming immune cell recognises an antigen – a molecule that the cell in this case falsely identifies as a piece of a foreign invader – and brings it to the lymph nodes, where another type of immune cell, the T cell, is then programmed to attack the antigen. For example, in multiple sclerosis, T cells are taught to recognise and attack the myelin sheath. Jewell thought it might be possible to prevent the T cells from learning bad habits by delivering an immune-system modifying agent directly to the lymph nodes.

The researchers injected an immune suppressive agent and the myelin antigen into the lymph nodes of paralyzed mice exhibiting a mouse model of multiple sclerosis. The infusion slowly reprogrammed the environment of the lymph node tissues to generate immune cells that migrated to the brain to stop the attack against myelin. These mice regained the ability to walk, and the effects lasted for the duration of the study, which was about 80 days. The mice were also able to readily respond when foreign molecules were introduced, suggesting that the treatment didn’t compromise normal immune function.

As a next step, the researchers have been testing the idea in other mouse models of autoimmune disease, including transplant models and models of type 1 diabetes – a disease in which the immune system attacks the pancreas. Later this year, the group will team up with clinicians at the University of Maryland Medical School to begin tests in non-human primates, another step closer to investigating this idea as a future human therapy.

This research was presented at a meeting of the American Chemical Society. A video on the research is available at www.youtube.com/watch?v=u3n0hbi7DdM.

Source: MS-UK (12/04/17)

Lifestyle risk factors in the progression of multiple sclerosis

Low vitamin D levels and smoking consistently associated with MS progression

MS is the result of a complex, and yet unknown, interaction between the genes that we inherit and the environment in which we live. Any risk factors that can be avoided by simple modifications, such as those changes in a person’s lifestyle, are particularly important because they may require a lower cost than other risk factors.

In this study from Southern California, USA, researchers reviewed previously published articles on risk factors and exposures associated with MS progression and summarised their findings. Of the 59 studies meeting inclusion criteria, they found that many studies reported

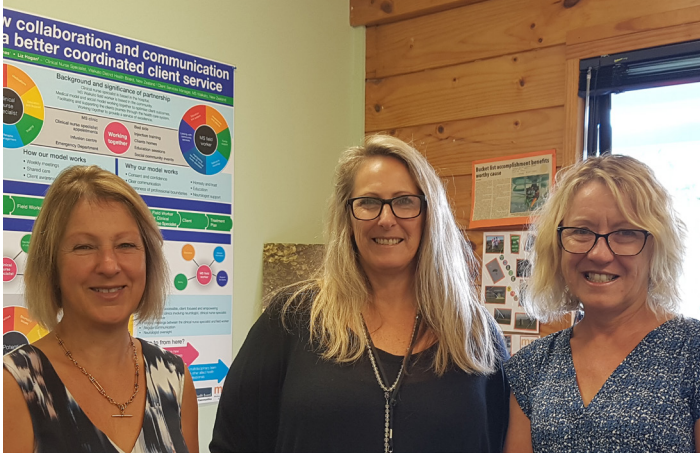
conflicting results or used different measures, making it difficult to draw any clear conclusions.

However, many of these studies agree that MS progression was consistently related to smoking and low levels of vitamin D were associated with higher EDSS scores. Smoking was also associated with a faster progression of disability in people with MS. The authors underlined the urgent need for more studies in different populations to further clarify MS risk factors in future.

See more at: www.msif.org/news/2017/03/08/lifestyle-risk-factors-progression-multiple-sclerosis/#sthash.igBIUlcA.dpuf

Source: MS International Federation

HD News



(L-R) Karen, Tracey & Liz

It has been a busy start to 2017 welcoming newly diagnosed clients and families to MS Waikato trust.

We provide information and education, support and advocacy to clients and families as they navigate their way through the changing and challenging journey of Huntington's. We also offer In-service education to care staff at rest and residential homes. MS Waikato subsidises an exercise class that is available to our members and is run in conjunction with Parkinson's Waikato.

Our educational evenings are an annual event, with guest speakers providing helpful information and knowledge to our families. This is also a great opportunity for families to meet and connect with others who are paddling the same canoe, so-to-speak. From time to time we host a carer's event or social gathering which

helps to strengthen the connections between families.

As the community link between our clients and medical personnel, we are here to support and assist with any issues and concerns you may have. We have a close relationship with the Neurology Department at Waikato Hospital, and are happy to sit in on any medical appointments as necessary.

If you require support, education and/or advocacy for yourself and/or family member, please do not hesitate to contact me at MS Waikato. Although I am the HD coordinator, my colleagues Liz Hogan and Karen Bird also work with our Huntington's families as required.

Our contact details are:

Tracey Larsen

Ph: 07 834 4745 or 027 385 5425;
email tracey@mswaikato.org.nz

Liz Hogan

Ph: 07 834 4741 or 027 428 7417;
email liz@mswaikato.org.nz

Karen Bird

Ph: 07 834 4742 or 027 777 1344;
email karen@mswaikato.org.nz

Also see our website www.mswaikato.org.nz

Tracey Larsen

AGM Updates

The MS Waikato AGM was held on 22 March, at this time Graham Haines retired from the board, Caroline Allbon has also recently retired. Many of you will know both Graham and Caroline who had both served on the board for over 10 years, had lead as Chairperson and given a lot of time, energy and shared knowledge, we would like to express our sincere thanks and appreciation to them both.

We are fortunate to have a strong and robust board and the Trust continues to be lead by our Chairperson, Leanne Milligan; other Trustees continuing are Mark Etheridge, Frankie Letford, Clare Simcock, Graham Derrick, Chris Luoni and Erin Burke.

ME/CFS and Fibromyalgia

MS Waikato also provides support services for people affected by ME/CFS and Fibromyalgia. We employ a qualified Field Worker and our services include the provision of information and education, advocacy and monthly support groups.

The ME/CFS and Fibromyalgia group have their own quarterly newsletter, Koru, which is written specifically to provide information and support to this client group.

If you would like to receive an electronic copy of this please notify Tracey by emailing: tracey@mswaikato.org.nz or phone 07 834 4745.

Have you seen our new Facebook page – MS Waikato

NOTICE BOARD

The Entertainment Book

MS Waikato are selling the Waikato/ Bay of Plenty Entertainment books again this year. For \$65 you will receive thousands of dollars worth of vouchers in our region. Books are also available for other regions. MS Waikato will receive \$13 from each book sold. A sample book is available in the office to view.

A flyer is enclosed, to order online go to www.entbook.co.nz/1b54128 or call into the office to purchase a book.

Donations and Bequests

Donations to MS Waikato can be made at anytime through our website www.mswaikato.org.nz, please click the link 'Donate now' 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/ 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.

Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

Subscriptions

Please note 2017 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.

World MS Day

World MS Day is taking place on Wednesday 31 May, this is a global awareness day and an opportune time for us to try to raise public awareness and understanding of MS. We will have awareness stalls and need volunteers to assist with this, if you are able to help, please phone Janet on 8344740 or email janet@mswaikato.org.nz.

Staff Contacts

Liz Hogan will be on annual leave for 6 weeks from Monday 8th May and back in the office Monday 19th June. During this time Karen Bird will be looking after those affected by Multiple Sclerosis, please contact Karen on 07 834 4742 or email karen@mswaikato.org.nz

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok. The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

Vitamin D3

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

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MSWT EVENTS CALENDAR



JUNE 2017

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5 Queens Birthday	6 MS Support Group Dawn till Dusk Cafe Te Awamutu 10am	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 MS Support Group Summerset Down the Lane Dixon Road 10.30am	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	31

JULY 2017

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 Dawn till Dusk Cafe Te Awamutu 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 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	25	26 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	27 MS Support Group Summerset Down the Lane Dixon Road 10.30am	28	29

AUGUST 2017

SUN	MON	TUE	WED	THU	FRI	SAT
		1 MS Support Group Dawn till Dusk Cafe Te Awamutu 10am	2	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 MS Support Group Summerset Down the Lane Dixon Road 10.30am	25	26
27	28 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	29	30 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	31		

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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