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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
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Janet - 07 834 4740**

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Mahi tatau ki te whakawhiwhi he hapori rawe



Ahoy there matey!



A notice forwarded to all MS clients inviting people to apply for a place on the Oceans of Hope's latest sea faring adventure prompted Jody Butler from Hamilton to put her name forward. Jody was diagnosed as having relapsing/remitting MS 4 years ago and has six weekly infusions of Natalizamab. She says "I love the water and I was really interested in learning how to sail so I thought I'd give it a go." Jody was accepted and in November last year she found herself walking down the gang plank of the iconic New Zealand sailing ship `Spirit of New Zealand`. "I was really nervous - I've never really spent any time with anyone else with MS and I didn't know what to expect".

What she got was 40 people from Norway, UK, Australia and New Zealand with varying disabilities and ages ranging from 35 - 70. "It was a bit awkward at first. We were all in two large rooms with horrendous sleeping arrangements (hammocks stacked 3 high) and absolutely no privacy!

`Oceans of Hope' is a UK based charity which has as one of its functions `The sailing sclerosis

project'. The aim is to change the perception of MS by showing what is possible when people with a chronic disease are empowered to conquer their individual challenges - to broaden their horizons either physically or mentally. The charity organises voyages all over the world for people with MS.

The voyage was a five-day trip sailing from Auckland to Tauranga anchoring in sheltered bays at night. "We had a go at everything you do on a sailing ship (yep - even swabbing the deck) and it was amazing learning new things and realizing you were capable of doing them. The crew were amazing - very patient and willing to help when needed." But Jody says the highlight was talking to the other participants and hearing their stories. "It was very special being with people who knew what I was going through and nice to see them achieving things." "In just 5 days we went from awkward strangers to best friends and no one wanted to leave once we had docked".

Following on from this experience Jody recently participated in another Oceans of Hope journey - in Turkey.....



Ahoy there matey! cont...

In early October Jody, along with two other New Zealanders and two Aussies flew off to Fethiye on the coast of Turkey. "It was really cool as four of us had been on the New Zealand trip so we were starting as firm friends".

Instead of one ship this time there were five much smaller boats with eight people on each. No crew this time just a captain. "This was a 100% different sailing experience - we did everything - even buying the supplies and cooking" says Jody "It was more `hands on`, more to do, more intimate and ultimately much more enjoyable". The other 35 `sailors` were made up of people from Denmark, UK and the Netherlands. "It was quite heart -warming watching them rock up on their scooters and wheelchairs or carrying canes".

The voyage itself was a five-day trip around the coast and back to Fethiye stopping in various bays over night for safety reasons. "It was beautiful - the weather great (28 - 30 degrees), warm, clear water and fantastic views".

At the end of the voyage, the group travelled together and spent five days in Istanbul and then went hot air ballooning in Cappadocia where they then parted company. Jody and one of her friends stopped off in Dubai before returning to New Zealand.

And so that's the end? Nope! In December, `Oceans of Hope` is staging another trip out of Auckland and around the Bay of Islands on racing yachts. And not just any ole racing yachts but former Whitbread around the world contenders Lion NZ and Sir Peter Blake's iconic Steinlager 2. "I have no idea what will happen" says Jody "But I've got my name down and I'm raring to go".

Ian Maxwell

If you would like information about the Oceans of Hope Challenge NZ 2019 please contact Liz - liz@mswaikato.org.nz or Janet - janet@mswaikato.org.nz



Neuropsychological testing

• What is Neuropsychological testing?

Neuropsychology is the study of the relationships between brain function and behaviour, cognitive functioning, and emotion. Testing usually involves the administration of standardised tests (i.e. tests that have been developed by assessing hundreds or thousands of healthy 'control' participants) that assess functions such as memory, attention, thinking speed, and executive functioning (i.e. 'higher level' thinking skills such as planning, inhibition, and problem-solving). At Waikato Hospital Neurology department, the testing is a screening assessment, with the clinical interview and testing process typically taking around 1-1.5 hours in total, as opposed to comprehensive neuropsychological assessment, which can often take several hours of testing.

• Why am I being sent for Neuropsychological testing

Some people with multiple sclerosis experience cognitive (i.e. thinking) changes either as a component of the condition or because of secondary factors such as fatigue or low mood. The assessment is designed to provide reliable information regarding your cognitive functioning, and any symptoms of low mood or anxiety. This information helps the neurology team provide the best advice we can regarding your rehabilitation and support. Some disease modifying treatments can impact on cognitive functioning, and so the testing also helps the neurology team understand the full effects of treatment.

• Who does the testing?

The neuropsychologist in the team is Dr Jamie Macniven, who trained in the UK as a clinical psychologist and then a clinical neuropsychologist, and who has been working with the team since he immigrated to NZ eight years ago. Jamie is currently a contractor for the DHB, and lives on the Hibiscus Coast, travelling to Hamilton every fortnight for two clinic days.

• Where is it done?

Level 1, Reception A of the Meade Clinical Centre, Waikato Hospital.

• What does testing involve?

There is a brief clinical interview for around 15-30 minutes; the testing then typically takes around 45 minutes, followed by completion of a mood-screening questionnaire. Jamie sometimes has a general idea of the results at the end of the assessment session and will then discuss this with you, but often it can be quite difficult to know exactly what the test results mean before the tests are scored, results interpreted,

and the information is put together in a formal report.

• Should I do anything to prepare for the test?

If you wear glasses for reading, please bring these with you to the assessment session. If possible, try to be as rested as possible so that you are able to give your best effort to the tests.

• How long will it take?

Usually around 1.5 hours.

• Will I get the results?

Jamie writes a report after the assessment, and sends this report to the referring neurologist and to Karen Clark, Neurology Nurse Specialist. The department also usually sends the report to your GP. You can obtain a copy of the report from the department or from your GP, and when you see your neurologist or Karen next, they will be able to discuss the results with you. If you want to see Jamie for further feedback after you have read the report, this can also be arranged.

• What is the benefit of me undertaking testing?

The main benefit is that the team can best understand your cognitive strengths and any areas of difficulty, and therefore make recommendations to support you with these difficulties, for example arranging help for any significant mood or anxiety difficulties we identify. We can also understand whether or not your cognitive functioning is changing over time by reassessing you periodically. This helps us to determine which supports you may require. Some new treatments for MS might have the potential to actually improve cognition over time, and this is the reported experience of some people with MS on these treatments. In the future we are hoping to use some of the (fully anonymised) data from the testing to determine if there are any consistent beneficial effects of treatment on cognition. For a small minority of patients there can be a small risk of cognitive impairment due to some of the MS medications; this is another important reason for us to monitor cognitive functioning over time.

Thanks to Karen Clark, Clinical Nurse Specialist and Dr Jamie Macniven, Neuropsychologist



Dr Jamie Macniven at Waikato Hospital Department of Neurology.



On the couch with Dr Jan Schepel



Jan Schepel

We had a great turnout from the MS community for our conversational evening with Neurologist Dr Jan Schepel.

Dr Schepel is head of the neurology department at Waikato hospital and is an expert on MS so we are very grateful that he joins us each year to bring the latest MS knowledge to our community. He discussed and answered questions on a broad range of topics, including diet, Vitamin D, stem cells, cannabis, phone apps, Ocrelizumab, trigeminal neuralgia and lumber puncture.



Jan and Keith (Trustee).

The conversations were lively with great audience participation, as with most groups there is such a depth of knowledge, ideas and experience collectively that I think we all learned something.

A lovely part of the evening is also the supper where we were able to mingle and informally chat with Dr Schepel and other attendee's over a cuppa and some nice food.

For those of you who were unable to attend and would like more information about the evening please contact Liz or Karen at MS Waikato.

Waikato Total Mobility Scheme

A nation-wide scheme providing people with disabilities mobility options. Registered users pay a 50% discount on taxi fares up to a maximum of \$30. The scheme is available to all ages who have a physical, intellectual, psychological, sensory or neurological disability that prevents them from accessing public transport. The Scheme is affiliated with Red Cabs, Hamilton Taxi's, Trikiso Buses Ltd and Driving Miss Daisy.



If you qualify for the Total Mobility Scheme this also entitles you to free bus transport around Hamilton 24/7. It costs \$25 to apply which covers the cost of your photo and access card Liz at MS Waikato is a registered assessor. If you would like to know more please ring Liz on 834 4741.

MS Awareness Week

We would like to express our thanks and appreciation to all those who volunteered on our stalls and to those who gave to our collectors. Throughout the week, we were able to raise public awareness and understanding of MS and the support services that are available. As well as several stalls in Hamilton, we also had stalls in Cambridge, Thames and Whangamata. A huge thank you to all of our volunteers who assisted with this, without your help this would not be possible.

In particular, we would like to thank Dave and Karyn who organised all the fundraising in Whangamata, Dave took along his ukulele and guitar and had songs pumping out for most of the day and Robyn who organised the stalls in Thames. Our stalls raised a total of \$3,328.



Maureen & Bill



Margaret and Amanda





14 October 2019

Update on the Phase III GENERATION HD1 study

Dear global HD patient community,

Today we are pleased to announce that we are increasing the total enrolment in the GENERATION HD1 study (NCT03761849) from 660 to 801 participants worldwide. We believe that increasing enrolment now - before study recruitment closes - keeps the study on track to complete within expected timelines. This study change does not impact participants already enrolled in the study, but it allows for additional patients to enrol in each of the three study groups.

The GENERATION HD1 study is evaluating the efficacy and safety of the investigational molecule RG6042 in people with manifest HD. The 25-month study is testing two dosing regimens compared to placebo - RG6042 once every two months (eight weeks) or RG6042 every four months (16 weeks). The open-label extension of the Phase I/IIa study is ongoing and supports the exploration of the two dosing groups in the GENERATION HD1 study.

Why are we making this change?

- **More data:** The additional number of participants will provide more data to equally evaluate both dosing groups, as well as increase the statistical power of the study. This is a technical study design term that refers to the study's ability to detect a treatment effect. In interactions with the HD community, we have learned the importance of testing both doses - while acknowledging that less-frequent dosing would be less demanding for patients, families and the overall healthcare system in the real-world setting.
- **More confidence:** Prior to GENERATION HD1, a study of this size involving an intrathecally administered investigational medicine has never been conducted in HD. Since the study started recruiting this summer, enrolment has been remarkably rapid worldwide. Based on the interest from the HD community, we are confident that a larger study can fully recruit.
- **More diversity:** Expanding recruitment allows for enrolment of more patients in different parts of the world. US recruitment in particular has exceeded expectations and is now complete. Therefore the additional participants will be enrolled from our network of existing trial sites in nearly 20 countries outside of the US to diversify the study population. Achieving broader global representation in clinical trials is important to our company, as well as health authorities around the world.

We are also pleased to announce that the GENERATION HD1 study is being extended to China. This will be the first time a study testing a Huntington-lowering therapy will be brought to the country. Information about Chinese study sites will soon be posted on ClinicalTrials.gov.

The community has been a critical partner throughout the development and progress of the GENERATION HD1 study. The speed of recruitment is thanks to the clinical-trial readiness and commitment of the HD medical and patient community to researching treatment options. We appreciate the partnership with the community and we look forward to providing future study updates.

Sincerely,

Mai-Lise Nguyen, on behalf of the Roche & Genentech HD team
Global Patient Partnership, Rare Diseases

M-XX-00000004



Genentech
A Member of the Roche Group

ms.

MS Waikato warmly invites you to an education evening with

Neurologist Dr Matt Phillips

To discuss:

Metabolic Therapies in Huntington's Disease

On Wednesday 4th
December 2019

6.15pm (for a 6.30pm start)

At The Link

(corner River Road and
Te Aroha Street)

This will be followed by a
light supper

Please RSVP by Wednesday
27th November 2019
Phone: 07 834 4745 or email
tracey@mswaikato.org.nz

A donation towards the evening
would be greatly appreciated
Collection pots will be at the venue.

You and your family are warmly
invited to our

HD FAMILY DAY OUT

The day will provide a lot of
fun and laughter,
an opportunity to connect
with others and will be a
great day out for the whole
family and carer's.

At Totara Springs
Matamata

On Sat 22nd Feb, 2020
10am to 4pm

Cost: \$10.00 per person

Any donations above this amount
will be greatly appreciated.

Morning Tea, Lunch and
Afternoon Tea provided

Please phone or email
to register by

Friday 25th January 2020.

Ph: 07 8344745

E: tracey@mswaikato.org.nz

We look forward to
seeing you all there



Important Telephone Numbers

Your Own Doctor

In an Emergency..... 111

**Need to talk 1737
(call free or text anytime to talk to a trained counsellor)**

Mental Health Helpline..... 0800 505 050

Dept of Work & Income 0800 559 009

Inland Revenue (IRD)..... 0800 775 247

Lifeline - Outside Hamilton (*open 24/7*) 0800 543 354

NZ Drug Foundation 0800 378 474

Tenancy Service..... 0800 836 262

Crisis Team (CAT Team) 0800 50 50 50

Suicide Prevention Helpline 0508 828 865

Anglesea Clinic..... 07 858 0800

Anxiety phone line 0800 269 4389

Citizens Advice Bureau..... 0800 367 222

Electricity Complaints..... 0800 223 340

Lifeline - Hamilton..... 07 838 0715

Mental Health Waikato Hospital 07 838 3752

Police - Central Station..... 07 858 6200

Victim Support Helpline..... 0800 842 846

Depression Help line (*open 24/7*)..... 0800 111 757

Samaritans (*open 24/7*) 0800 726 666

Health Line..... 0800 611 116
(*advice from Registered Nurses, open 24/7*)

Your local Rural Support Trust
..... 0800 787 254 (0800 RURAL HELP)

Alcohol Drug Helpline (*open 24/7*)..... 0800 787 797
(*you can also text 8691 for free*)

Are You OK0800 456 450 (family violence helpline)

Gambling Helpline0800 654 655

Shine 0508 744 633
(*confidential domestic abuse helpline*)

Quit Line.....0800 778 778 (smoking cessation help)

Women's Refuge Crisisline.....0800 733 843
(0800 REFUGE) (for women living with violence, or in fear,
in their relationship or family)

Youthline (*open 24/7*)..... 0800 376 633
You can also text 234 for free between 8am and midnight,
or email talk@youthline.co.nz

ME/CFS & 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.

Reduce stress at Christmas and avoid over exertion

- 1. Make a List** - It works for Santa! Checking items off a list gives a sense of accomplishment and is satisfying in itself.
- 2. Prioritise** – Attend to what is most important and set your own realistic boundaries. Avoid being caught up in the frenzy of Christmas. It is important to attend to the evergreen basics - sleep, rest and eating well.
- 3. Lower others expectations** – Be realistic by creating your own idea of the 'perfect' Christmas that suits you and your family.
- 4. Buy online** – No need to cope with busy shopping centres but order early so they arrive on time.
- 5. Delegate** – A problem shared is a problem halved.
- 6. Learn to say no** - Learning to say no to others' demands can be a struggle at this time of year, so start thinking of your needs when family and social activities are being planned.

MS Waikato Trustees and Staff would like to wish
you all a Happy Christmas and a safe and prosperous New Year.

NOTICE BOARD

Subscriptions

Please note 2020 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.

Payments

If you wish to make any payments directly to MSWT please pay into account number 02 0316 0488196 000 Please remember to include your name and what the payment is for eg Subs.

Christmas Lunch

Join us for Christmas lunch at the Hamilton Workingmen's Club, 45 Commerce St

2 course buffet lunch, this is being subsidised by MS Waikato for those who have paid 2019 subs

Date: Thursday 12th December

Time: Lunch will be served from 12.30pm, entry from 12.00pm

Cost: \$13 for financial members or \$23 for non-financial members.

Bookings are essential

Email janet@mswaikato.org.nz or phone Janet on 07 834 4740 by 9th December.

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.

Christmas Closure

The office will close on Friday 20th December and re-open on Monday 20th January.

TravelScoot

We now have a TravelScoot available for short term loan for a donation. For more information contact Liz, Tracey or Karen.

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.

Exercise Classes

The last exercise class before Christmas will be on Wednesday 18th December, the classes will re-start on Monday 6th January.

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 carolestark22@gmail.com

Dogs in Homes

For the safety of our staff please ensure all dogs are secured when staff visit.

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 8344741 or email liz@mswaikato.org.nz

Thanks to our Sponsors and Supporters



WDFW Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West
Glenice & John Gallagher Foundation • Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central
Stockbridge Trust • Len Reynolds Trust • The Norah Howell Charitable Trust
Waikato Lyceum Charitable Trust

MSWT EVENTS CALENDAR

December 2019

SUN	MON	TUE	WED	THU	FRI	SAT
1	2 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3	4 MS Exercise Class HD Educational Evening The Link, Te Aroha St 6.30pm	5	6	7 MS Walking group 9am The Veranda Cafe Hamilton Lake
8	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	11 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	12 Christmas Lunch Hamilton Workingmens Club	13	14 MS Walking group 9am The Veranda Cafe Hamilton Lake
15	16 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	20	21
22	23 Office Closed	24	25 Christmas Day	26 Boxing Day	27	28
29	30	31	Office closed Monday 23 December to Monday 20 January			

January 2020

SUN	MON	TUE	WED	THU	FRI	SAT
			1 New Year's Day	2 New Year's Day holiday	3	4
5	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	7	8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	9	10	11 MS Walking group 9am The Veranda Cafe Hamilton Lake
12	13 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	14	15 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	16	17	18 MS Walking group 9am The Veranda Cafe Hamilton Lake
19	20 MS Exercise Class Office Re-opens	21	22 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	23	24	25 MS Walking group 9am The Veranda Cafe Hamilton Lake
26	27 Auckland Anniversary	28	29 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	30	31	

February 2020

SUN	MON	TUE	WED	THU	FRI	SAT
						1 MS Walking group 9am The Veranda Cafe Hamilton Lake
2	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4 MS Support Group Dawn to Dusk Cafe Te Awamutu 10.00am	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 Waitangi Day	7	8 MS Walking group 9am The Veranda Cafe Hamilton Lake
9	10 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13 MS Support Group Hamilton Cafe at Summerset 206 Dixon Road, 10.30am ME/CFS Support Group Methodist Church Bader St, Melville, 10.30am	14	15 MS Walking group 9am The Veranda Cafe Hamilton Lake
16	17 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	18	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20 MS Support Group Mometewa Te Aroha 10am	21	22 MS Walking group 9am The Veranda Cafe Hamilton Lake
23	24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27	28	29 MS Walking group 9am The Veranda Cafe Hamilton Lake

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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