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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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20 Palmerston Street
PO Box 146, Hamilton 3240**

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**Liz - 07 834 4741
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Julie Blanks – Don't Mess with this Lady!



Julie Blanks

Julie Blanks from Te Aroha is a woman with a larger than life personality, a rakish grin (complete with a gold tooth) and a penchant for trying to kick people in the head. Julie is a 1st dan black belt Feast Tae Kwon Do practitioner who achieved this level despite the slight inconvenience of having relapsing/remitting MS.

What Julie used to be was a keen snowboarder. One day back in 2015 while gliding down Whakapapa she lost her balance and wiped out breaking her tailbone. Her Osteopath patched her up and she was soon back on the mountain's slopes – and falling over again, this time giving herself concussion. "I just kept on falling over!" says Julie. "The Osteopath could see there were other things going on and suggested I be referred to a specialist". She was sent for an MRI scan and was diagnosed with MS in 2016. By this time, she found she was getting fatigued easily, had tired limbs, slow reaction times and couldn't sleep.

Julie had taken up the art of Feast Tae Kwon Do in 2014 after she had enrolled her children in the local Dojo. "I was really interested in what they were learning and thought I would give it a go myself". As MS zapped her energy, she didn't grade for a year after achieving her Brown Belt.

Julie found she had to retrain her brain – especially her memory and spelling – a process that is ongoing. Being frustrated that she couldn't remember how to tie her shoe laces up and forgot how to spell Beast. She used and continues to use, apps like Wordscape, Codycross, Four Pics One Word and Mahjong on her tablet to keep her brain active and relearning. She has also recently found a drug that suits her and gets a Natalizumab drip every 6 weeks that helps with her energy levels and decreases the chances of having a relapse.

As an entity Tae Kwon Do was developed during the 1950's by Korean Martial Artists with backgrounds in the Japanese

Julie Blanks – Don't Mess with this Lady! con...

and Chinese arts. It has an emphasis on speed and agility and is characterised by leaping movements and head high kicks. Although it can be a competitive sport (introduced to the Olympics at Sydney in 2000), Julie's school does not take part in competitions and prefers to hone their own art and work on personal aspects. As well as physical skills, students must master the mental aspects such as integrity, perseverance and self-control. Learning to centre herself, controlling her breathing and calming the mind has benefits for not only her, but also her family for other sports, exams, and paid employment etc.

Feast Tae Kwon Do has 10 levels of competence starting at white belt and working through to black belt. Once a black belt there are a further ranks known as dans or degrees. You are considered a Master of the art when you get to the 4th –6th dans and a Grand Master from 7th -9th dan.

To get her black belt Julie had to undergo a 6 hour examination intermittently throughout the school's triannual grading. During this time, Julie had to

demonstrate her proficiency in patterns, fundamental techniques, self defence by sparring, fitness, mental discipline and self confidence. And, yeah, she actually had to break bits of wood and tiles with her hands and feet.

At the time Julie was on a daily medication which made her feel sick and wasn't really working for her. She says the examination really pushed her to her absolute physical limits and took a few weeks to get over. "There's no way, I could have done it without the amazing support of my family especially my husband, my Instructor, other Black Belts and my Grand Master. It was definitely a group effort, but at the end of the day, I certainly had to push myself to my absolute limits and believe I could do it. It doesn't stop now, but now I'm working on not deteriorating, falling over or at least making the best of a rubbish situation. Also how can I snow board with my family again?"

Julie's husband and son should join her in the black belt ranks by the end of the year and her daughter should achieve the feat in the next couple of years

Ian Maxwell

Liz's Melbourne Marathon for MS and HD

Our client services manager Liz Hogan recently completed the Melbourne marathon. Liz said it was hot, windy and difficult on the course. She said that when it got really tough she thought about her clients and how some of them have huge challenges on a daily and weekly basis and she drew inspiration to keep going. Liz said running the final lap of the MCG (Melbourne Cricket Ground) was a special moment in the run.

Liz finished the 42km run in 4 hours 53 minutes and 15 seconds raising a whopping \$2,125 for MS Waikato. Thanks to everyone who supported Liz and the fundraiser.



Liz - at the beginning



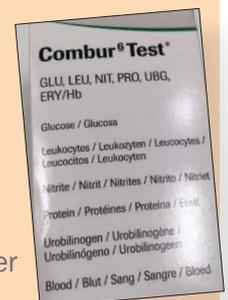
Liz with medal

Dipsticks

You are now able to purchase urine dipsticks for \$27.20 for a pack of 50 from the Pharmacy on Meade, Level 1, Meade Clinical Centre, Waikato Hospital.

These maybe useful if you suspect you may have a urinary tract infection and you can test your urine at home.

Please contact your GP or Neurology Outpatients if the results are positive to assess whether further action is required.



MS Education Evening

We had a great turnout for our recent MS Education evening with Neurologist Jan Schepel. Jan was accompanied by Sophie Wills, Data Administrator, Neurology Research.

This year's topic was on the MS Base Registry and the importance that this registry has for MS patients. As Jan said "This powerful pool of data can be used to address many important questions about MS, and will ultimately help to improve the lives of people living with MS.

So what is the MSBase registry?

Sophie introduced us to the MSBase registry, which is an international online registry for neurologists studying Multiple Sclerosis. Waikato DHB along with Christchurch DHB are part of the pilot scheme to bring MS Base to New Zealand.

This registry collects and stores data from MS clients from all over the world who have volunteered to participate in this. The purpose of the MSBase Registry data collection is to conduct analyses that links patient characteristics and treatment with specific outcomes. It is an important research tool in helping to develop the best possible treatments for MS patients. Clients consent to having their medical information put on the database. This information includes demographic data, medical history, diagnostic information on MS, blood tests, other tests, MS treatments, allied health specialists involved and client visits to medical appointments. Their name and personal details remain anonymous to researchers when their information is used in a study.

Sophie showed us examples on spreadsheets of how this data can be used for individual clients and for statistical information. For the neurologist this means that their client's medical details are all in one place, allowing them easy access to their medical treatments and to follow the client's progress over time.

Dr. Jan Schepel talked about the importance of the MSBase Registry for MS treatments now and in the future. So far, there are 61,910 MS clients from 43 countries, participating with the database. At present 50 clients in the Waikato have given consent to be included on the database.

By collecting the MS client information on one site it provides researchers with a huge wealth of data for them to study the many different questions that MS raises.

Dr Schepel went on to present some of the recent studies that have come out of MSBase and

demonstrated how their results can help change and/or improve MS treatments. It is anticipated that this evidence-based research will improve outcomes for people with Multiple Sclerosis by changing clinical practice.

An example on how the information gained from the MSBase registry can be used to improve treatment options was that of our national body, MS New Zealand using evidence of outcomes for people provided with early treatment intervention. The information is included in a submission to Phamac asking them to lower the criteria for those with relapsing and remitting MS, to enable more people to benefit from the disease modifying drug treatments.

If any clients want to be part of the MSBase Registry a consent form can be obtained from the neurology department at Waikato Hospital or from MS Waikato.

If you would like to know more about MSBase information can be found at:

<https://www.msbase.org/>.

Additional information can be found on the New Zealand Multiple Sclerosis Research Trust website;

<https://msresearch.nz/msbase-introduced-to-new-zealand-allowing-people-with-ms-in-to-participate-in-international-research/>



Sophie and Jan

Maintain Good Nutrition

You Can...Maintain Good Nutrition

We all know the adage, “You are what you eat.” Maintaining your health is one of the first steps to managing MS, and a big step to maintaining your health is eating well every day.

Eating well does not require eating expensive or unusual foods. Quite the opposite. Simple foods from the basic food groups will serve your body and your health.

You CAN maintain good nutrition--and here are ten ways to get started.

Ten Ways to Improve Your Diet

1. Eat three fruits every day. Keep a bowl of fruit on hand to satisfy those sugar cravings.
2. Add beans to your diet. Black bean soup, bean burritos, red beans and rice, and bean dip are examples.
3. Increase your vegetable intake. Double up veggies at your evening meal. Add sliced tomatoes to your lunch. Snack on raw vegetables.
4. Stop eating when you are satisfied. Be aware of portion sizes—most restaurant meals could feed two people. Take leftovers home for another meal.
5. Eat whole grains such as brown rice, whole wheat bread, and whole grain cereals.
6. Enjoy two sources of low-fat dairy products every day: milk, yogurt, cheese.
7. Use olive oil or canola oil.

8. Limit saturated fat. Read the labels. And remember that fatty meats or cheeses, butter, and whole milk products have large amounts of saturated fat.
9. Eat three meals every day. People who skip meals tend to make up the calories anyway.
10. Drink more water. Plain water. It's caffeine and calorie free.

There's more to nutrition. A good diet can help you fight fatigue as well. Here are five tips:

Nutrition Tips to Help Manage Fatigue

1. Never go longer than four hours without food. You don't have to eat a lot. Have a small snack.
2. Shrink your meals so you eat more frequently. For example, save half your lunch and eat it three hours later.
3. A small protein snack in the afternoon, such as cottage cheese, or peanut butter may make you more alert.
4. Avoid big helpings. Avoid sugary desserts. Both will increase fatigue!
5. Avoid over use of caffeine. If you use caffeine as a pick-me-up throughout the day, it may lead to restless sleep and increased anxiety.

With a little effort, and a pinch of will power, You CAN feel better, fight fatigue, and maintain good nutrition!

Source: <https://www.nationalmssociety.org>

Pat Simpson

Karen Clark, Clinical Nurse Specialist Neurology has recently been joined by Pat Simpson in Neurology Outpatients Department, Waikato Hospital. Pat is thrilled to be filling the large shoes of Kat, Neurology Nurse, who has moved on to work full time in the Eye Clinic. Pat has a long history with the Neurology Department at Waikato Hospital, having been the Clinical Nurse Specialist for Neurology and the Stroke Services prior to leaving to further her studies.

As the neurology nurse she will be working with Karen to provide a targeted person-focused neurology service. “I am delighted to be back as part of the neurology department working with such an amazing team. I am looking forward to getting to know all the people living with MS, and HD, their families and Whanau plus the wonderful team that support you all in the community”.



Pat and Karen

HD News

Apathy Linked to Physical, Cognitive and Behavioural Disability in Huntington's Patients, Study Finds

Apathy is linked to physical, cognitive, and behavioural impairments in patients with Huntington's disease, a study shows.

The study, "Relationships Among Apathy, Health-Related Quality of Life, and Function in Huntington's Disease," was published in The Journal of Neuropsychiatry and Clinical Neurosciences.

Huntington's disease is characterized by the accumulation of toxic protein aggregates inside nerve cells, affecting the cells' ability to work and eventually killing them. As the disease progresses, patients experience motor, cognitive, and behavioural changes.

Up to 90% of Huntington's patients also experience apathy, defined as a marked by a reduction in goal-directed behaviours, including self-care, social interactions, and mobility. Indeed, apathy can be one of the most disabling behavioural symptoms for both patients and their caregivers.

Previous studies have suggested that apathy can be a useful clinical marker of disease progression. But it is unclear if it precedes motor impairments or occurs early in the disease course. Several reports have linked this behavioural symptom with disability across different disease stages.

To better understand the association between apathy and functional, motor, cognitive, and behavioural outcomes in Huntington's, researchers analysed clinical data covering 471 patients. Among them, 193 had the genetic mutation linked to the disease but

had not yet developed clinical symptoms (prodromal stage), 187 had early stage disease, and 91 had late stage Huntington's.

Apathy levels differed by stage of disease, with individuals in the prodromal group, not surprisingly, showing lesser apathy than those in the early- and late-stage groups.

Higher expressions of apathy related to lesser independence, greater motor impairment, and more clinician-rated behavioural problems (defined as anger, irritability, depression), across all groups of patients.

Apathy levels were also high in patients who reported having poor health-related quality of life. Measures of poor life quality included greater chorea (abnormal involuntary movements), greater upper- and lower-extremity dysfunction, greater speech and swallowing difficulties, high levels of anxiety, depression, and poor cognitive function.

"These findings are consistent with work in other neurodegenerative diseases and suggest that clinical interventions should consider targeting apathy," the researchers wrote. "It appears to be rather pervasive in terms of affecting multiple aspects of functioning and health-related quality of life."

The team believes that additional studies are necessary to evaluate the potential impact that "clinical interventions targeting different functional domains" may have in easing apathy in Huntington's patients.

Source: huntingtonsdiseaseneews.com

MS Waikato warmly invites you to an education evening with two of New Zealand's leading HD researchers;

Dr. Malvinder Singh-Bains, PhD & Dr Nasim Mehrabi, PhD

To discuss Pushing the Research Frontiers to Unlock the Secrets of Huntington's Disease & an update on HDYONZ (HD Youth Organisation)

Friday 7th December 2018

6.30pm (Doors open 6.15pm)

The Link (corner River Road and Te Aroha Street)

Followed by a light supper

Please RSVP by Monday 3rd December 2018

Ph: 07 8344745 or email tracey@mswaikato.org.nz

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

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, Te Awamutu, Morrinsville, Thames and Whangamata. A huge thank you to all of our volunteers who assisted with this, without your help this would not be possible.

We would also like to thank the Cambridge Lions, Unichem Pharmacy Cambridge and Noel Leeming Cambridge for your support. The stalls raised a total of \$2,276.



Heather and Fran

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.

Movie Night Fundraiser

In October we screened "King of Thieves" as a fundraiser at the Lido.

As in previous years, we had a great response to this with a full house on the night. We would like to express our thanks and appreciation to Gavins for the donation of popcorn, the Lido and Gothenburg for raffle prizes. Thank you to all who came along and supported this too. The evening raised \$1,175

IMPORTANT NUMBERS TO REMEMBER

- Your Own Doctor
- Anglesea Clinic07 858 0800
- In an Emergency..... 111
- Anxiety phone line.....0800 269 4389
- Mental Health Helpline.....0800 505 05
- Citizens Advice Bureau.....0800 367 222
- Dept of Work & Income..... 0800 559 009
- Electricity Complaints.....0800 223 340
- Inland Revenue (IRD).....0800 775 247
- Lifeline - Hamilton..... 07 838 0715
- Lifeline - Outside Hamilton.....0800 543 354
(open 24/7)
- Mental Health Waikato Hospital.....07 838 3752
- NZ Drug Foundation.....0800 378 474
- Police - Central Station..... 07 858 6200
- Tenancy Service..... 0800 836 262
- Victim Support Helpline..... 0800 842 846
- Crisis Team (CAT Team).....0800 50 50 50
- Depression Help line (open 24/7)..... 0800 111 757
- Suicide Prevention Helpline..... 0508 828 865
- Samaritans (open 24/7)..... 0800 726 666

- Health Line open 24/7 0800 611 116
advice from Registered Nurses,
- Your local Rural Support Trust..... 0800 787 254
(0800 RURAL HELP)
- Alcohol Drug Helpline 0800 787 797
(open 24/7), you can also text 8691 for free
- Are You OK..... 0800 456 450
family violence helpline
- Gambling Helpline..... 0800 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.....0800 376 633
(open 24/7) You can also text 234 for free
between 8am and midnight, or email talk@youthline.co.nz

The Trustees and Staff would like to wish you a Happy Christmas and a safe and prosperous New Year



NOTICE BOARD



Christmas Lunch

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

2 course buffet lunch, this is being subsidised by MS Waikato for those who have paid 2018 subs

Date: Thursday 13th December

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

Cost: \$10 for financial members or \$20 for non-financial members.

Bookings are essential – email janet@mswaikato.org.nz or phone Janet on 07 8344740 by 10th December.

Christmas Closure



The office will close on Friday 21st December and re-open on Monday 21st January.

Exercise Classes

The last exercise class before Christmas will be on Wednesday 19th December, the classes will re-start on Monday 7th January.

Subscriptions

Please note 2019 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 the Trust bank account this is 02 0316 0488196 000

Please remember to include your name and what the payment is for eg Subs.

Alinkers



MSWT has 2 Alinkers which are for client use.

If you are interested in trialling an Alinker for about 6 weeks please contact Liz for further information. The Alinker is available to all MS clients within our region.

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.

Wheelchairs

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

Client Survey

Thank you to those who completed the recent client survey. The response was fantastic and we appreciate your feedback. The results from surveys help us to tailor our services to best meet your needs.

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.

Thanks to our Sponsors and Supporters



Sir John Logan Campbell Residuary Estate



WDFW Karamu Trust • Waipa District Council • COGS- Hamilton City, Hauraki, South Waikato & Waikato West • Anytime Fitness - Hamilton Central • Stockbridge Trust • Riverside Golf Club • The Sutherland Self Help Trust • The Gallagher Charitable Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Glenice and John Gallagher Foundation • The Hamilton Club • Cambridge Lions

MSWT EVENTS CALENDAR

December 2018

SUN	MON	TUE	WED	THU	FRI	SAT
30	31					1 MS Walking group The Veranda Cafe, Hamilton Lake 9am
2	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	7 HD Educational Evening The Link Te Aroha St 6.30pm	8 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 Christmas Lunch Hamilton Workingmens Club 	14	15 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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	21	22
23	24	25 Christmas day	26 Boxing day	27	28	29
Office closed 24 December 2018 - 18 January 2019						

January 2019

SUN	MON	TUE	WED	THU	FRI	SAT
		1 New Year day	2 Day after New Year day	3	4	5
6	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	11	12
13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15	16 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18	19
20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25	26 MS Walking group The Veranda Cafe, Hamilton Lake 9am
27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	30 MS Exercise Class MS Support Group Absolute Café Cambridge 10.am	31		

February 2019

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

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