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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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Totara Springs



The Totara Springs MS camp was a great success, everyone enjoyed the time together. We were very busy with a large range of fun activities including; kayaking, shooting, rock climbing, foam slide, flying fox, swimming, top town team games, BMX, go carts, flying kiwi, tubing, rock climbing, human foosball, archery, Burma trail, water slides, playground, jumping pillow, mini golf, an education session for the kids and a fun quiz with great prizes.

We are so thankful to the individuals and organisations that supported the camp, it would be very difficult to put it on without this help.

The connections people make with each other is one of the most valuable aspects of camp as the ongoing friendship and support can be invaluable.

Here are some of the feedback comments from clients who came along.

"Amazing family camp! Seeing the children having so much fun, especially on the water slides was my highlight as well as catching up with old friends"

"The camp was really cool. I enjoyed

making new friends and loved the accommodation"

"The place is awesome. I loved all the activities especially going tubing down the river and spending loads of time in the pool. I can't wait to visit new friends!!."

"It has made wonderful memories for us together."

"I must admit I had reservations about going to the camp but meeting others, in a relaxed atmosphere just made the camp."

"Fantastic weekend, awesome people"

"Loved the quiz night with the prizes"

"Another great camp"

"Excellent, special needs catered for, amazing"

MS Waikato would like to thank the Stockbridge Trust, WEL Energy Trust and Multiple Supplements for their generous support in funding the camp.



Totara Springs



The Michael Ford Memorial Golf Tournament

Our annual golf tournament took place on Friday 13th April. This tournament was originally established by one of our members – Michael Ford who sadly passed away at the end of 2017, it has now been running now for 19 years on the Lochiel course at the Riverside Golf Club and is one of our major fundraisers.

On what was quite a blustery day we teed off with a field of 52 players and raised a total of \$6,430.

Overall best Stableford was awarded to Kerry Kirk, with Joanne Ford joining us to assist with the prizegiving ceremony.

Thank you to our generous sponsors and to the players without which the tournament would not be possible. Thank you also to our wonderful volunteers – Ian, Bruce, Sue, Kylie, Joanne and Jeremy who gave up their time to assist on the day.

Our sponsors help in a variety of different ways, some making a monetary donation, others donating prizes or services for the day. They choose to do this to help make a difference; all funds raised remain in our region to assist with the provision of support and education services for our clients and their families.



Please do remember our sponsors and support them too

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12 Ways to Improve Memory With MS

Memory problems may be common with multiple sclerosis, but you can improve and protect your cognitive abilities with these expert tips and strategies.

Expert Advice for MS Symptoms

For some people with MS, recent memory is impaired, which makes trying to recall something learned recently, like the name of a new neighbour, a challenge. For others, the difficulty is with long-term or remote memory – you may find it hard to remember learned skills, such as playing a game you enjoyed years ago, or even tying shoelaces.

Almost 60 percent of people with Multiple Sclerosis experience some sort of memory problems, according to the US National Multiple Sclerosis Society.

Certain strategies can help you exercise your memory and make remembering a bit easier.

Perception or Reality?

Your memory may not be as bad as you think, says Laura Lacritz, PhD, professor of psychiatry, neurology, and neurotherapeutics and associate director of neuropsychology at UT Southwestern Medical Center in Dallas. “While dysfunction can be seen in MS, perceived memory difficulties are often related to reduced attention and slowed processing speed, which are among the most prevalent cognitive changes seen in MS,” she says.

With this in mind, methods to improve memory are rooted in techniques that enhance attention and the ability to process information. Lacritz points to promising studies showing that people with MS who were slower to learn new information were able to retain the material at the same rate as those without MS.

Strategies to Improve Your Memory With Multiple Sclerosis

Lacritz offers the following 12 suggestions to help with memory at home, at work, and on the go:

1. **Get good sleep.** The brain restores itself and consolidates information during sleep.
2. **Reduce distractions.** Especially when you need to learn something new, cut out visual and audio clutter. For example, designate periods of the day for tasks that demand concentration and ignore emails and phone calls during that time. Set a separate time for responding to messages.
3. **Don't put off tasks.** Schedule demanding tasks or activities earlier in the day when you have the most energy.
4. **Focus on one task at a time.** That means no multitasking. Stick with one project until you're finished, then move on.
5. **Leave yourself reminders.** If you have to stop in the middle of a task, jot down a note so you know where you were when you pick it back up.
6. **Repeat new information to enhance learning.** This may involve having information reiterated to you, then you repeating it back and making a written note of what was said. This multimodal learning (hearing, speaking, and writing) can enhance later recall.
7. **Give yourself enough time to process new information.** Before switching to a new topic or activity, review the information, ask questions, and repeat the information back as needed. The key is to make sure you have adequately processed the information. If the information never gets in, it isn't likely to be recalled later.
8. **Use written lists and reminders.** The act of simply writing out a list can help you remember tasks. Make a list at the end of each day for the following day, and then review the list in the morning and prioritize what needs to get done.
9. **Stick to routines.** Creating a routine makes tasks – such as taking medication and doing household chores – easier to remember.
10. **Make exercise a regular part of your routine.** In particular, aerobic exercise has been shown to improve cognitive function among those with MS.
11. **Manage fatigue.** Fatigue can be one of the most debilitating MS symptoms and can compromise your cognitive function. To lessen your fatigue, try delegating tasks to others, pacing yourself, and exercising – yes, exercise can help fatigue, too.
12. **Be alert for signs of depression.** Depression can contribute to attention problems and fatigue, making it more difficult to learn. Depression can also exaggerate memory impairment.

<https://www.everydayhealth.com>

By Mikel Theobald

Reviewed by Farrokh Sohrabi, MD

Protein Structure that causes Huntington's Disease REVEALED

Huntingtin protein's structure is now clear thanks to cryo-electron microscopy. This is kind of a big deal

By Caroline Casey on April 03, 2018

Edited by Dr Ed Wild

The cause of Huntington's disease has been known since 1993, but the physical structure of the healthy *huntingtin protein* proved difficult to discover until now. German scientists have now revealed the shape of the *huntingtin protein* for the first time. Although the structure of the mutant form of the protein was not investigated, this study provides an excellent platform to build upon and will boost drug development efforts.

Know your enemy

One of the biggest issues in HD research to date is that although we know what causes the disease - a harmful protein called mutant huntingtin. We even know some ways in which the mutant protein wreaks havoc within the human brain. But until now we've had no idea what the protein actually looks like. That makes trying to prevent it causing damage very difficult! Imagine you're a farmer whose crops are being damaged by an animal every night. If you had a photo of the animal that was causing the damage, it would be easier to figure out how to prevent it. A drunk elephant would require a different strategy from a swarm of locusts. It's the same when we're fighting brain diseases: knowing what a protein looks like is a huge help when it comes to understanding how it operates and how to make drugs to change its behaviour.

Things tend to slow down when it gets cold. Cryo-electron microscopy uses low temperatures to hold protein molecules still, then an electron beam captures hundreds of 'photographs'.

Cool science – literally

The technique used in this particular study is the *crème de la crème* of microscopy, so much so that it was awarded the Nobel Prize for Chemistry last year. It's called *cryo-electron microscopy*, otherwise known as *cryo-EM*. It involves shooting a beam of electrons at a sample that's been frozen using a super-cold liquid. When we say cool we don't mean like a beer or a smoothie – this technique involves cooling proteins to several hundred degrees below freezing.

When the electrons hit the sample, it causes them to scatter slightly before striking an electron detector, which builds up an image like the light detector in a

digital camera. But one image isn't enough - hundreds of 'photos' have to be taken from different angles, then combined by computer to reveal the 3D shape of the protein.

The images generated by cryo-EM are so precise that the authors of this study – a team led by Stefan Kochanek at the University of Ulm – were able to document the structure of huntingtin down to a billionth of a centimetre! The study found that the protein was essentially composed of two parts, connected by a bridge region. This is a very important finding as it suggests that the function of huntingtin could be to act as a kind of protein hub. In other words, it's a mothership that lots of different protein spaceships dock into.

What's the big deal?

You might be thinking to yourself, why has it taken such a long time to figure this out? Basically, it's due to how complicated and bendy the *huntingtin protein* is. In order to build up a 3D image of the protein, it has to be photographed from multiple different angles, but for the pieces of the puzzle to slot together perfectly, the protein has to remain in the same position for this entire process. Unfortunately for us, this doesn't happen with the *huntingtin protein* alone. To get around this, the researchers of this study used another protein called 'huntingtin-associated protein 40' or *HAP40*, which was able to bind to both segments of *HTT* as well as the bridge region and essentially fix it in one position, to stop it moving around. This stabilised the protein for long enough that the 'photoshoot' could take place.

What about the mutant protein?

Dr Kochanek unveiled the structure of huntingtin (the squiggly ribbons) in February at the therapeutics conference, as a birthday present to the HD community celebrating 25 years since the discovery of the gene.

The structure that was just announced was of the normal, healthy huntingtin protein that scientists call 'wild-type'. But what about the structure of mutant huntingtin? Surely we need to know the what that protein looks like, to actually help in HD?



On the one hand yes, there is still an urgent need to identify the structure of the harmful version of huntingtin, and that would be super-helpful for

HD News

designing therapies to combat the mutant protein's harmful effects. However, that poses a whole host of other potential challenges to researchers.

Unfortunately, the presence of the mutation changes the way the protein interacts with other proteins. That's probably one of the things that makes it harmful. Remember that the success of the photoshoot depended on huntingtin sticking to another protein, HAP40. But the presence of the mutation may mean that huntingtin and HAP40 no longer stick together so well, meaning the cryo-EM photoshoot doesn't work so well. The authors hinted at this problem in their article.

How can this help?

The structure of the mutant protein will hopefully come in time, now that the healthy one has shown its face. But just knowing the structure of the healthy huntingtin protein is already a big deal. Despite decades of research, we still don't understand all the jobs huntingtin carries out in our cells, not just in the brain but the whole body. But since the structure of a protein basically dictates how it interacts with other molecules, we can now use these results to work out what different functions huntingtin might have, and how it achieves them. Essentially, this finding is a lightbulb that means we're no longer shooting in the dark to understand and reveal huntingtin function.

Finally, this finding will be a big boost for efforts to invent new drugs to fight Huntington's disease, especially if it does lead to uncovering what the mutant protein looks like. It could enable the design of targeted drugs that make the huntingtin proteinless toxic whilst protecting the helpful functions of the healthy protein. Hopefully, this discovery will kickstart a new era for targeted drug development in Huntington's

disease, focused on the known structure of the huntingtin protein.

The authors have no conflicts of interest to declare. For more information about our disclosure policy see our FAQ...

Glossary

Huntingtin protein The protein produced by the HD gene.

Wild-type the opposite of 'mutant'. Wild-type huntingtin, for example, is the 'normal', 'healthy' protein.

HTT one abbreviation for the gene that causes Huntington's disease. The same gene is also called HD and IT-15

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AGM Updates

The MS Waikato AGM was held on the 28 March, at this time Clare Simcock, Frankie Letford and Chris Luoni retired from the board. Our Trustees all work in a voluntary capacity and we would like to express our sincere thanks and appreciation to them for the time they have given and the knowledge they have shared.

We are fortunate to have a strong and robust board, Mark Etheridge has taken on the role of Chairperson, our other Trustees are Leanne Milligan, Marsha Marshall, Graham Derrick and Mike Tuck.

LIGHT UP 4 HD



May is HD Awareness month and around the globe landmark structures are lit up in the HD colours of blue for adults and purple for children. Hamilton City Council is kindly supporting this campaign and will be lighting up Anzac Parade Bridge between 14 – 18 May, so take a look if you are out and about in the evenings during this time. We will also be holding an information stall at Chartwell Shopping Centre on Thursday 17th May. I will be asking for volunteers to help out on the stall so please phone Tracey on 8344745 if you can help.

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.

NOTICE BOARD

World MS Day

World MS Day is taking place on Wednesday 30 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 an awareness stall at Chartwell and need volunteers to assist with this, if you are able to help, please phone Janet on 8344740 or email janet@mswaikato.org.nz.

Alinkers

MSWT has 2 Alinkers which are for client use. If you are interested in trialling an Alinker for 6 weeks please contact Liz for further information. Please understand that there is an expectation that you will keep track and report your usage for a 4 week period while you have the Alinker. This is open to all MS clients within our region.

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.

MSWT Walking Group

Join our MS Walking Group led by Lisa Andrew
Every Saturday morning ...rain or shine
9am at Lake Rotoroa (known as Hamilton Lake)
Friends, family, pushchairs, wheelchairs, Alinkers and dogs on leads all welcome!!
Lisa will be identified wearing a MS t-shirt.

Wheelchairs

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

Dogs in Homes

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

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.

Entertainment Book – 2018/2019

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.

Subscriptions

Please note 2018 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..

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 e.g. Subs.

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.

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

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MSWT EVENTS CALENDAR

June 2018

SUN	MON	TUE	WED	THU	FRI	SAT
					1	2 MS Walking group The Veranda Cafe, Hamilton Lake 9am
3	4 Queens Birthday	5 MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	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 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	28	29	30 MS Walking group The Veranda Cafe, Hamilton Lake 9am

July 2018

SUN	MON	TUE	WED	THU	FRI	SAT
1	2 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	4 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	5 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	6	7 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	13	14 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 MS Support Group Morrinsville Mometewa 10.am	20	21 MS Walking group The Veranda Cafe, Hamilton Lake 9am
22	23 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	26	27	28 MS Walking group The Veranda Cafe, Hamilton Lake 9am
29	30 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	31				

August 2018

SUN	MON	TUE	WED	THU	FRI	SAT
			1 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	2 MS Support Group Hamilton Cafe at Summerset Down Lane 206 Dixon Rd 10.30am	3	4 MS Walking group The Veranda Cafe, Hamilton Lake 9am
5	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	7 MS Support Group Dawn to Dusk Cafe Te Awamutu 10am	8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	9 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	10	11 MS Walking group The Veranda Cafe, Hamilton Lake 9am
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 MS Support Group Matamata Mometewa 10.am	17	18 MS Walking group The Veranda Cafe, Hamilton Lake 9am
19	20 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	21	22 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	23	24	25 MS Walking group The Veranda Cafe, Hamilton Lake 9am
26	27 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	28	29 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	30	31	

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