ms.
Multiple Sclerosis
Waikato

ManuScript

Working Together to Provide a Service of Excellence
Mahi tatau ki te whakawhiwhi he hapori rawe

Issue 65 - May 2020

Inside:

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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S.P.A.N. Trust

‘One day while walking down the street...’

Gary Cairns was a builder (and an ‘A’ grade squash player - i.e. pretty good) when he was diagnosed with relapsing/remitting MS at the age of 30. He is now a 47-year-old Property Developer (and no longer plays competitive squash - last game 2018), he tells us the story of what happened ‘one day walking along a Hamilton street’...

“Having been a member of Greenpeace for a couple of decades and receiving pamphlets about their progress against commercial whaling ships in Antarctica waters, peaked my interest to visit the beautiful continent one day. My health was not good during 2018 due to a medication allergy; I was pleased to see the end of it.

February 2019, I was walking down Victoria St in Hamilton and saw a travel agency sign. I got an overwhelming feeling. I had not done a lot of travel in the past so I think it was fear and excitement when Antarctica came to mind. I thought with no hesitation “Just Do It!” As I entered the room, six travel agents behind their desks all seemed to look up at me at the same time. I threw my hands in the air and asked, “How do I get to Antarctica?” After being welcomed, I booked my dream trip for 10 Nov – 3 Dec. I had some months to get as fit as I could.

I flew from Auckland to Buenos Aires, Argentina. Then took a domestic flight to the most southern city in the world, Ushuaia. Here is where I boarded the ship Expedition. The majority of the 134 passengers from all over the world were there individually for their own reasons, like me. There was only one other Kiwi from the South Island. I personally challenged myself to cross the deepest and roughest channel in the world named after Sir Francis

‘One day while walking down the street…’ *(continues)*

Drake, “The Drake Passage” with no medication offered for seasickness, there and back. The crew often reminded us all to prepare for the worst, this was not a cruise ship, it was an expedition. Half of the passengers stayed in their cabins sleeping off the seasickness during the crossing.

At 5am, my whole body was moving on the bed with my head hitting the wall. I thought bugger this, I’m going outside to see what is going on. I put on my gear and climbed the stairs to the top front of the ship. I held on tight to the rail. It felt like a rollercoaster ride. Head on to swells the size of a house with -20 degree 50-knot winds. No land in sight. I looked around and noticed I was the only person up here. It was really emotional for me to experience this. I tried to throw my arms in the air with joy but had to hold on. I experienced this for half an hour before anyone else came up. After two days at sea we made it to Antarctica.

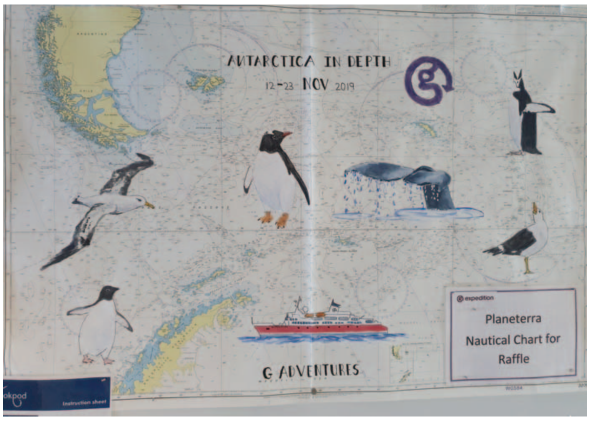
I was in a unique group of twenty kayakers. We kayaked six times for three hours each, six different locations and weather. With 18 hours daylight, we made the most of it including several exertions to shore. It never rains in Antarctica and the weather can change with little warning, from a fine sunny day to cloudy and snowing in a few hours. One time I had to abort the kayak into a zodiac at sea as the gentle breeze turned into gusting winds.

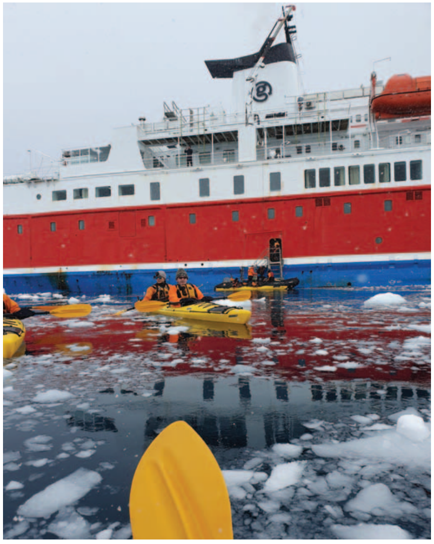
We got up close to penguin colonies, seals bathing in the sun, albatrosses and whales. The landscapes were so massive it was breath taking.

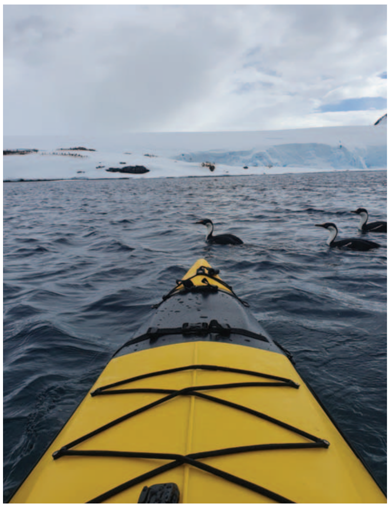
Back on the ship in the lounge there were speakers. New Zealand was one country that was spoken highly of by all the crew on a number of occasions. I feel so proud to be from New Zealand.

If there is anything on your bucket list, “Just Do It!”

Gary Cairns







Managing change in the Covid-19 environment

Since the arrival of Covid-19 we have been navigating through challenging times and a changing daily routine. We're have experienced lockdown, the daily hustle and bustle has come to a halt, we have had to learn social distancing and new ways of shopping and interacting with others and we're seeing a drastic shift in society.

The ever-changing dynamic of the virus can leave many feeling uncertain. Uncertain of when it will end, when we will begin to see our efforts pay off, will we go back to the old "normal" – the one we're used to and what might the new normal be.

While anxiety is a normal and expected reaction to Covid-19, too much anxiety can start to cause harm. Feeling stressed and fearful every day takes a toll on health and well-being very quickly. Although we remain uncertain on a number of factors, we remain resilient and confident in our ability to overcome this hurdle.

To help us navigate these challenging times, here are some helpful reminders:

Take care of yourself. Be kind to yourself. It is important to take time for yourself to look after both your physical and mental health. Eat as well as possible, exercise regularly, get enough sleep, and make time for hobbies and activities you enjoy. Go easy on yourself if you are experiencing more depression or anxiety than usual.

Accept what is out of your control. Focusing on things you have no control over will leave you feeling frustrated and exhausted. You cannot do anything to change certain circumstances, so it's best to let go of them. Doing so will help you focus your energy on the positive. Remember – though you may not be able to change these realities, you can change how you respond to them.

Embrace change. There will always be change. Instead of concentrating on the disruptive aspects, take a flexible approach and accept that change is a fundamental part of life that can also bring opportunities and positive outcomes. A very useful exercise is to ask yourself or others what positive changes have you experienced or what have you learned during this time?

Maintain a positive attitude. Resilience doesn't mean you have a positive feeling about every negative situation. It means that despite something going wrong, you believe you can and will do your best to deal with the situation and move forward. Practice reframing – what are the potential benefits? Can we turn this challenge into an opportunity?

Connect with others. One of the most important ways that we enhance our resilience is to spend time with other people. Having people around you with whom you can share feelings, discuss problems and receive advice is an essential part of weathering life's storms. It's also important to reach out for help when you feel overwhelmed by a situation.

https://www.tcenergy.com/stories/2020/2020-04-15wellness-wednesday---managing-change-and-uncertainty-during-covid-19/

Neurology Clinic

We hope that throughout the pandemic everyone has remained healthy and well.

The neurology outpatient department has remained open during the pandemic and a lot of clinics have occurred over the phone which has proved to be successful.

Special authorities over this period have been extended by 3 months so people do not need to worry if they have not been seen in clinic for their annual assessment as usual.

We have been continuing with our Natalizumab infusions as scheduled and those on oral medications or the injectables have continued as normal.

Those who are about to start or are already on Ocrelizumab may be postponed depending on their individual situation. These patients have been contacted.

We want to reassure all our patients that they can contact us if they have any concerns as we are here and working as normal.

Karen Clark
Clinical Nurse Specialist: Neurology
karen.clark@waikatodhb.health.nz
or phone 021 412 025

Karen Clark

MS Waikato and why we ask for subscriptions

Our vision is ‘People Living Their Best Lives’, to achieve this our staff work closely with people who are newly diagnosed, supporting them with reliable, robust and up to date information together with symptom management strategies for themselves and their family. We continue with information and education 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, 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

Now, more than ever we need your support by paying your subscriptions.

As many of you will know MS Waikato is a charitable trust, we are a non-government organisation and as such don’t receive any funding to employ our wonderful Client Services staff – Liz, Tracey and Karen. To enable us to provide services to you and your family we are usually dependent on grants, fundraising, subscriptions and donations. However, due to Covid-19 many funders are not currently able to support community organisations with grants, we have also had to cancel our annual golf tournament.

At present 30% of you, our clients, have paid subscriptions. If everyone were to pay their subs this would amount to approximately $16,000 a year, please don’t think that yours doesn’t matter, it does, it all makes a difference and helps ensure that our staff are here to help when you or your family need their support.

If you have not yet paid your subs for 2020, it would be greatly appreciated if you could please do so to help ensure that we are able to continue to provide our services. If you are unsure if you have paid for subscriptions please email me - janet@mswaikato.org.nz, I am happy to check this and advise you.

Subs are $40 per year, or $20 if you have a community services card. We appreciate that for some people this may be a large payment, if you need to pay in instalments, we are happy for you to do so, if you could just get in touch with me and let me know you wish to do this.

Payments can be made directly to the Trust bank account – 02 0316 0488196 000, please remember to include your name and what the payment is for e.g. subs.

A huge thank you to those of you who have already paid.

For anyone who wishes to make a donation a receipt will be given and you will be able to claim the tax back on this.

Thank you for your support and stay safe.

Janet Buckingham

AGM Updates

The MS Waikato AGM was held on the 25 March, as we prepared to go into lockdown, this was held via Zoom.

We are fortunate to have a strong, robust board and our board members remain the same, however we have a couple of changes in roles. Marsha Marshall has stepped down as Chairperson with Desley Clarke being nominated for and accepting the role of Chairperson. Marsha will continue as our Deputy Chairperson, our other Trustees are Mark Etheridge, Mike Tuck, Graham Derrick, Keith Small and William Hughes.

Desley is the Human Resources Manager for Enrich Life at Life Unlimited and has been on our board of Trustees for almost 2 years.

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.

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.

HD Family Day - Ngatea Water Gardens

What a great day our HD families had at the Ngatea Water Gardens on a perfect sunny March day. The picturesque gardens provided a relaxed atmosphere for everyone to meet and mingle as we meandered around, enjoying the quirky signs, the friendly ducks, peacocks, goat and sheep. We finished the day with a picnic lunch provided by Ngatea's own The Glory Company Café.

We would like to thank the Cambridge Lions for their generosity in funding this day.

Tracey Larsen

What does COVID-19 mean for Huntington's disease families and HD research?

COVID-19, short for coronavirus disease 2019, has taken the world by storm in almost every sense – many people have been infected with the SARS-CoV-2 virus, it's created shopping pandemonium in stores, and many people are isolated at home. But behind that frenzied storm, scientists around the world have been working tirelessly to move research forward at an unprecedented speed so that we can understand the virus and develop a treatment or vaccine. How does this situation affect the HD community? And what does COVID-19 mean for HD research?

What does COVID-19 mean for HD patients and families?

A key question for many in the HD community right now is: Am I, or is my loved one, at greater risk for COVID-19 because of HD? The answer to that is – it depends. On its own, having the genetic mutation that causes HD doesn't make anyone more or less susceptible to COVID-19 than someone without HD.

What would make an HD individual more susceptible to COVID-19 is if they had any underlying conditions that put them in the "high-risk" category. Those can be as obvious as having asthma or being a smoker. But this can also include HD individuals who are symptomatic since we know that swallowing, clearing secretions from the lungs, and self-understanding of limitations can be impaired by HD.

Advice from various global HD organizations can be found here:

- https://www.hda.org.uk/getting-help/covid-19-information-advice
- https://hdsa.org/wp-content/uploads/2020/03/COVID-Statement-3-18-20-final.pdf
- https://www.huntingtonsociety.ca/novel-coronavirus-covid-19-and-huntington-disease-what-you-should-know/

"On its own, having the genetic mutation that causes HD doesn't make anyone more or less susceptible to COVID-19 than someone without HD. What would make an HD individual more susceptible to COVID-19 is if they had any underlying conditions that put them in the "high-risk" category. "

To stay safe and healthy we should all continue doing what the WHO recommends – wash our hands regularly for 20 seconds with hot water, clean surfaces with a disinfectant, and practice social distancing. Social distancing means only coming in contact with members of your household and only going out for essential things, like an essential job, grocery store run, or to get medication from the pharmacy. Everyone should also remain vigilant for the symptoms of COVID-19, which include fever, a dry cough, shortness of breath, and fatigue. Some HD patients at particularly high risk may need to isolate themselves even more strictly. You should seek advice from the above sources and your health provider if you are concerned.

What does COVID-19 mean for HD research?

Many scientists who usually spend all day in the lab studying HD have been asked to stay home so that they can practice social distancing and remain safe. This means that HD-related research will slow for the short time during this pandemic. A big concern is ensuring that precious samples are kept safe, and experiments that had to be shut down were paused in a way that preserves them to be restarted once it's safe to hang out in the lab again.

While HD researchers may not be going into lab every day, they're still hard at work to combat this disease. They may not be doing experiments at the bench, but they're reading papers to develop their next idea, compiling data to better understand HD, and writing papers to disseminate what they've learned to the world. The labs may be quieter, but HD researchers are still hard at work in their fight against HD.

What about clinical trials?

With many countries' entire healthcare systems turned over to providing care for people with COVID illness, and many doctors and nurses diverted from research into frontline care, an impact on Huntington's disease clinical trials is inevitable. However, all those involved are doing everything they can to minimize the impact and carry on with whatever trial activity they can.

In practice, the impact will vary quite a bit from one site to another, and from one trial to another. Some sites may still be enrolling new patients, while many will be forced to pause recruitment of new participants and focus on continued care and dosing of patients already involved. Many sites will likely convert onsite trial visits into telephone calls, or postpone visits until it is safer to carry them out in person.

Decisions about what activity can carry on are largely determined locally, by the hospitals and local and national governing bodies that direct healthcare resources. Trial sponsors (companies like Wave, Roche and UniQure) fund, support and organize the trials. So far, all the trial sponsors we've heard from have indicated that they continue to be committed to running and completing the trials despite the interruption the viral pandemic may cause.

It may be that some modifications need to be made later, to compensate for trials that were unexpectedly interrupted. For instance, they might need to treat existing patients for longer, or recruit additional patients to make up for lost time. And later, the regulatory agencies like the FDA might need to be more flexible when considering data from trials with higher than normal levels of missing data. With so much unknown about how long COVID will impact things, it's difficult to be more specific, but the smart people who invented this cool generation of HD drugs and brought them to trials, are now working full time to keep those trials running as well as humanly possible.

Could there be a silver lining?

Science and research, and public policy informed by science not superstition, are the key to getting humanity through this crisis. The challenge has already changed scientific research for the better, in some quite fundamental ways, that could provide benefits long after COVID-19 is an unhappy memory.

In a very short time, scientists from around the world have united to study the virus and share their findings to benefit everyone. The number of scientific publications about COVID-19 is rising dramatically week after week.

In an effort to increase the pace of research about COVID-19, nearly all relevant scientific literature has been made open access, meaning it's currently available for free to everyone – for now at least. You can see just how much work is being done to understand and combat COVID-19 at LitCovid (and read as much as you want!): https://www.ncbi.nlm.nih.gov/research/coronavirus/

Research has already told us a lot about the virus. We know it can be spread from person-to person, either through direct contact with someone else who has the virus or by coming in contact with droplets produced by someone who has the virus, such as a sneeze or a cough – similar to how the flu is transmitted. However, COVID-19 is unlike the flu in many ways – it's much more fatal, we currently have no vaccine against it, and it's a new virus so we still have a lot to learn.

It can take up to 14 days after SARS-CoV-2 exposure to bring on COVID-19 symptoms, which is why many doctors are recommending a 14 day isolation period. However, we are now learning that a portion of the population may remain asymptomatic. This means they show no symptoms, but do have the virus and can pass it to other people. In fact, the asymptomatic portion of the population may be as high as 20 to 30%! This is why social distancing and staying at home when possible are critical for not spreading the virus – without widespread testing, we don't truly know who does or doesn't have the virus, so isolation is the key to staying healthy.

Dramatic rollout of drug trials

Many members of the HD community already have a head start on understanding how important clinical trials are for determining the safety and function of drugs before they're distributed widely. It's something HD patients and families are learning right now first hand with the Roche Phase III Tominersen trials (formerly Ionis-HTTRx and RG6042), and it's something that will also have to be done, in an accelerated way, for any drug used to combat COVID-19.

For COVID-19, researchers are trying to start on second base by repurposing drugs that are already approved by the FDA for something else, but may have an alternative use for helping COVID-19 patients. Because they're already approved and on the market, they've already passed safety trials, making them faster to use.

The WHO (World Health Organization) prioritized 4 such drugs or drug combinations that they think have the best chance of working against COVID-19 and have established a global trial to determine how well these drugs work, called SOLIDARITY – a fitting name for the global effort that has come together to work against this virus.

Remdesivir is a drug that prevents viral replication, which means it stops the virus from increasing in number. It was initially designed to combat the Ebola virus, and has shown promise for COVID-19. The drug that has gotten the most attention, at least in the United States, is chloroquine, a derivative of which is called hydroxychloroquine. While some people remain eagerly optimistic about this drug, it has limitations and still needs to be tested. The third drug is a combination of ritonavir and lopinavir, which has been approved to treat HIV infections. The last drug is the same combination of ritonavir and lopinavir with the addition of interferon-beta. Interferon-beta helps regulate inflammation and has shown promise in treating a different viral disease, MERS (Middle East Respiratory Syndrome).

This too shall pass

This virus has undoubtedly brought a stressful and scary time for the entire world, but there have been a few bright spots. And while the pandemic will eventually fade away, we will be left with its silver lining. Many have been able to spend additional time at home with loved ones, even if that means having a computer on their lap. Scientific discoveries are being made at breakneck speed as the global research community comes together to fight a common goal. And last but not least, dogs around the world are rejoicing that their 2 legged friends are spending every night staying in. So stay safe and stay healthy, for this too shall pass.

Information sourced from HDBuzz.net

NOTICE BOARD

World MS Day – 30 May 2020

This is a global awareness day, a day to celebrate global solidarity and hope for the future. Perhaps you may wish to share stories or connect with others to help raise public awareness.

Vitamin D

With winter on the way, if you do not take regularly take Vitamin D3, now is a good time to start.

These can be purchased through pharmacies or online.

Support Groups

All support groups are currently meeting via Zoom, staff will advise when support groups are able to resume in their traditional format.

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.

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.

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

Subscriptions

Please note 2020 subscriptions are now due, if you have not already paid them. If you are unsure, please contact Janet – janet@mswaikato.org.nz
The cost for subscriptions is $40 or $20 if you hold a Community Services Card.
Thank you for your support.

Payments

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

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