



Greetings everyone,

I'm writing from my home office which is now my very familiar place of work in my living room. These days a remarkable day is one during which I speak to someone face to face, not via phone, Zoom or email.

We are adaptable aren't we; we have somehow adjusted to a new way of being, with its many challenges, and its pleasures. One of the blessings has been the remarkable autumn weather which I'm sure has made this time enjoyable for outdoor exercise, or standing patiently in the supermarket line. I must say I have enjoyed shopping on line for potting mix to repot my bulbs, and some of the big projects I had on my list have been completed over this lockdown time.

It's our pleasure to send you our newsletter hot off the press. We were almost at the point of going to print with it when NZ was thrust into level 4. Our staff debated about how and when to send it to you - we've made some adjustments and here is our final version.

With level 2 on the horizon we are hopeful that we can soon be back in our usual work place. There are still unknown factors, but we will let you know how this might work, and whether we can provide exercise classes or gym sessions. In the meantime, we hope that everyone is keeping moving and being active in whatever ways you can. If you need some help with this let us know



Robin working from her home office

We have been doing our best to deliver our services from our homes, phones and computers. Of course we all acknowledge it is not the same as meeting face to face, but nevertheless we are lucky to have the technology be able to continue to connect in a personal way. The nurses, physiotherapists and physio assistant, group exercise leader, and social activities coordinator have all been busy making contact with members, responding to queries and offering support. We know that people have been very much appreciating this, but if there is anyone who has any questions or concerns, or needs more contact with which we can help, please don't hesitate to let us know and we will do whatever we can to respond.

Looking forward to seeing you in due course,

With warmest wishes for health

Robin

President's Message

I trust that this finds you and yours well. What strange times we live in. We will meet again, but will we shake hands again?

While we appreciate that everyone is facing increased pressures due to the pandemic, it is still necessary for us to consider the future of MSPC. Our society continues to grow, and we need to adapt and evolve to meet changing and varying needs. This means we are looking at offering more online consultations, exercise classes and support groups, and on the fundraising front, Lynne Trowbridge and the fundraising team are exploring options for virtual events and online initiatives. We need a solid platform from which to deliver all of these, and a major website upgrade is now urgent see details on page 4.

In these difficult times it's always good to have something to look forward to. Below is the concept graphic of the proposed BrainTree building.



As I write, we are about to go unconditional on the land purchase at Langdon's Road, so thank you very much to Simon Challies and Brendan Prendergast for personally backing this project, and to all the directors for their commitment and effort. I look forward to updating you further as we progress towards our next milestone.

Tessa Kain

president@ms-pd.org.nz



Manager's Message



Member survey

Thanks to everyone who completed our survey, whether it was online or the paper version. We do appreciate you taking the time to give us feedback.

Lucky members Nick and Jacqueline won the prize vouchers.

Our member survey told us the following:

We had 157 responses from 849 people emailed, which gives a response rate of 18.5%.

Women 56%; men 44%. MS – 48.3%; Parkinson's - 49.6; Other – 2%.

Age ranges as follows:

Age	%
25—34	2.7
35—44	5.3
45 –54	18
55—64	16.7
65—74	34.7
75—84	22.7

Overview of services deemed to be excellent or very satisfactory

Service	%
Home visit by nurse	89
Physio assessment	91
Phone contact with nurse	85
Exercise classes	91
Open gym	75
Yoga	99
Communication maintenance	91
Power of dance	89
Nordic walking	78
Café morning teas	85

There were some good suggestions such as a handbook for living with Parkinson's. We have several such books in our library.

There was a question about the Living Well Programmes, which continue to run each year and are always well attended. We haven't run the Minimise Fatigue, Maximise Life course for people with MS for some time as we don't currently have a trained facilitator. We are hoping to rectify this later in the year.

Someone commented that the nurses always seem busy, and that the Parkinson's nurse has too many clients. We are aware that our nurses work with a high number of clients, and they work very hard to try and see as many people as they can. We try to keep reasonable contact with our members through group activities, such as morning teas and peer support groups held at a variety of times. This year we have set up a weekly clinic day so people can see Anna, the Parkinson's nurse, at our office by phoning Donna-Marie or emailing to make an appointment. Our nurses will do their best to respond to you in a timely manner.

Remember the survey was anonymous, so if you have a query about your specific situation, please contact us directly. For example, if you are not receiving the newsletter and want it to be mailed to you, phone Donna-Marie our office administrator and let her know. Alternatively, you can always download it digitally through our website.

Please don't feel that you must wait for a survey to let us know your thoughts, ideas or feedback. We welcome your emails, phone calls, or in person chats. Our door is always open.

Robin Furley

manager@ms-pd-org.nz

From the Fundraising Office

This has been a tough couple of months for every sector, and we are no different. Unfortunately, as you may have seen, we have had to cancel or indefinitely postpone many of our events. At the moment, we are not sure whether or not our Annual Street Appeal will be going ahead or whether it may be taking a different form this year. We will keep you posted.

However, throughout this tough time, we have seen how loyal our supporters are. We want to sincerely thank those who have paid their membership subscriptions for this year and those who have been able to give a little extra. Your contribution, no matter how big or small, is very greatly appreciated.

Despite this tough time, MSPC know we are incredibly lucky to have such loyal members and supporters.

If you wish to find another way to give, there are a few ways you can continue to support listed on this page.

Ways to help

Payroll giving: Ask your employer to subscribe you to this through IRD. This is a great way to give, as it goes out of your pay before it reaches your account, so you won't even notice it going!

A new set of wheels for our Parkinson's nurse

MSPC were extremely fortunate to receive a grant from Manchester Unity Welfare Trust Board. Part of this grant allowed us to purchase a lovely new car for Anna, our Parkinson's nurse, to aid her work for those in the aged care community. The car will be much more efficient and ready to travel the long journeys Anna often finds herself on!

New website: We really need to update our website. There were many comments in our recent survey alluding to the inadequacies of the current website. The estimated cost for this project is \$10,000. If you know of anyone that might be able to contribute to this project, please get in touch with Lynne.

Entertainment App: This handy app gives you money off hundreds of restaurants and local businesses, which includes takeaways! You can still support our local businesses and save a little money at the same time. Entertainment gives a portion of the profits to the charity directly. Buy your membership with them here [\[Entertainment\]](#)

Donations: Any amount is appreciated and please remember to only give if you are able. You can donate through [Givealittle](#) or you could donate directly to our account: *The Multiple Sclerosis and Parkinson's Society of Canterbury (Inc)*, BNZ Account Number: 02 0800 0969020 00. If you do wish to donate via cheque, please ensure that you write the Society's full title, including both MS and Parkinson's.

For more information please contact Lynne or Charlotte, we would love to hear from you.

Lynne—366 2857 ext 8
fundraiser@ms-pd.org.nz

Charlotte 366 2857 ext 9
fassistant@ms-pd.org.nz

Paul Haglund and Sue Riley from MUWTB were present at the official handing over of the vehicle on 9th March. Our sincere thanks to them for their continued support.



From our bubbles

Anna—Parkinson's nurse

Hi everyone, your friendly Parkinson's nurse Anna Fraser here!

Like others in the organisation I'm working from home as is my hubby Tom. And, we have five teenage boys in the house all trying to continue their online schooling so it's fair to say our rural internet is getting a fair thrashing.

Our Labrador, Q, doesn't seem to know what to do with all of us being around! Still, she looks pretty happy to me!



I'm spending my time getting up to date with admin, filing and other office-based tasks that often take a backseat while I'm flat-out with home visits, on the phone and generally helping our many members. I'm also keeping in contact with members over the phone and video conferencing and able to offer advice and assistance whenever required.

There are a few things I want members to be aware of during these uncertain and somewhat unsettling times; the first and most important consideration is the mental health and wellbeing of members, their carers and those around them. COVID-19 is having a significant impact on how we interact with others and go about our daily lives. We know that this, combined with the stress of uncertainty can have an impact on our mental wellbeing.

For information and resources to support your mental health and wellbeing, see [Mental health and wellbeing resources](#) at Mental Health Foundation.

If you feel you are not coping, it is important to talk with a health professional. Call your regular health care provider or for support with grief, anxiety, distress or mental wellbeing, you can



call or text 1737 – free, anytime, 24 hours a day, 7 days a week – to talk with a trained counsellor.

Here are additional useful online resources

- Getting Through Together is a mental wellbeing campaign focused on things we can all do to maintain our mental health and wellbeing during the COVID-19 pandemic (All Right? and the Mental Health Foundation)
- Looking after mental health and wellbeing during COVID-19 advice and information, and useful top tips to get through (Mental Health Foundation)
- Stories of people's journeys to wellness and ideas to help you find your own way to better wellbeing (Depression.org.nz)

Useful Self-help tools –see page 11

Dedicated Healthline 0800 number for COVID-19 health advice and information is 0800 358 5453 it is free & available 24 hours a day, 7 days a week.

It is important that you take care of yourself. By doing so you will be able to continue to provide support to someone else.

Maintain a healthy lifestyle by eating well, getting adequate rest and sleep, and try to remain as physically active as you can.

At this stage it's a little unclear when I will be able to return to 'business as usual' & continue with home visits & other direct interaction with members. However, the Society will keep you up to date with these details as they become clearer and, in the meantime, please don't hesitate to contact me if you require any assistance at all.

Phone 022 474 2918

Look after yourself and keep connected

Judy—MS Nurse

Believe it or not, I'm enjoying this isolation and hope that certain aspects continue after restrictions are lifted.

I'm finding the slower pace of life so much calmer and have been making a point to meditate and to read each morning, before I begin work in earnest. Sometimes life gets so busy I had been finding it tricky to add reading into my day other than bedtime.

I also like routine; it has added a gentle structure to the start of my day, and I feel a greater sense of calm and clarity 'It's definitely put things into perspective for me.'

In the beginning of this isolation finding the right spot to work in was important, it couldn't be my downtime spaces so I set up a place in a little corner of the lounge room (we don't use it a lot at this time of year) as my new work space. Emma Jane Unsworth (author) wrote it doesn't matter where your desk is, all you need is just a small space to be facing outwards. Well, my space is facing a wall; it seems to work okay.



It also means I can leave work life behind at the end of my day.

I'm definitely enjoying a new way of communicating with folks while a lot of contact is by phone or email I was initially skeptical that using virtual mediums such as Zoom or Veeva would be a reasonable replacement and in some cases its not, however for meetings and some Peer Support Groups its been a good experience especially that folk can still communicate and be part of the group without leaving the comfort of their home.

It's been important to make sure we get out for a walk once a day, have regular breaks and be kind to ourselves.

Physios—Tara, Anna & Jill



Tara doing a Telehealth call from her home office.

Physios Anna King and Tara Martin, and Jill Morris (physio assistant) are still working hard during lockdown. For the first few weeks they focussed on making sure our regular open gym and exercise class attendees had exercise programmes they could continue with at home. Jill has done a great job continuing to support everyone with weekly phone calls and Anna and Tara have been completing Telehealth physiotherapy appointments. We are using a great new system called PhysiApp for most of our appointments. Not only does this system allow us to see you for our appointments, but it also has lots of exercise videos we can share and our usual information sheets uploaded to share. For those less familiar with technology, we have also used Zoom and a good old fashioned telephone call to help support our members. It has been wonderful to hear from members how they are coping with the lockdown and doing their best to keep up with their fitness goals. Some members, understandably, though are struggling more than others and we know that stress can make the symptoms of MS and Parkinson's much more pronounced. We have been providing education and exercise on stress management, relaxation and breathing to help these members. Lastly, the physios have used a bit of this time to streamline some of our documentation, touch base with our exercise group leaders, and make some plans for the future when we can go back to seeing members face to face. Unfortunately we don't know when this will be, as even at level 2, many of you will still be encouraged to self isolate. However, don't be a stranger and if you need us please get in touch. Kia Kaha!

Frances – Nordic walking instructor



Since March 28th our Friday Nordic Walking group members have been determined to continue meeting together, going on-line using Zoom! Our leader, Frances Young, sends out links to 'Virtual Nordic Walking' meetings each week via email to members. "Zoom software is free and easy to download. Our Nordic Walkers have joined to catch up with their Nordic Walking chums in our virtual meeting space" says Frances. "It's been a joy to keep the contact going with our wonderful Nordic Walkers." Recently the meetings have been taking on a themed aspect: with 'wear a jaunty hat week' and 'show and tell sessions' Frances recalls how: "Members have been sharing their memories and holding a treasured item or photograph up to the camera for us all to see. We have kept an element of surprise and joy continuously, this week it's a favourite song relating to a photograph of ourselves from earlier times."

Our lovely members have had plenty of good things to say about their virtual meetings too:

Richard Wetthey says: "Such a - great job Frances is doing with our on-line Nordic Walking group! It has become something very special on many levels."

Alister Marin say: "Frances puts a lot of work into our online meetings and I am thankful and enjoy our meetings very much."

Tammy Black says: "The session today, with our photos and our favourite songs, was a blast, everyone chose such cool songs it was another fun fabulous Zoom get together!"

Graeme Keeley says: "While we all have a common affliction, Parkinson's, we all have diverse backgrounds and this provides some semblance to normal life, where you are always meeting someone who comes from a different background but has a common interest or outlook to yourself and which often leads to a new friendship. Nordic walking fits this pattern admirably and hopefully we can soon all have a great coffee together after a strenuous exercise session and a brisk Nordic walk around Hagley Park!"

Staying connected with Zoom



Oceans of Hope



In December, several of our members took part in the Oceans of Hope 2019 New Zealand Challenge with MSNZ. From the 2nd to the 6th December, they sailed, worked and slept on one of two amazing racing yachts. It was a huge coup for Oceans of Hope to get Steinlager 2, formerly owned by Sir Peter Blake, and Lion New Zealand, which are both pedigree 80ft racing yachts. One of our members and committee member, Ingrid Robertson, was instrumental in bringing Oceans of Hope from the UK to New Zealand. The Managing Director of Oceans of Hope UK, Robert Munns, went as far as to say, “without Ingrid’s patience, enthusiasm and tenacity we would never have completed this challenge.”

The fine calibre of the racing yachts meant that the challenge was much harder than it had been in previous years. The accommodation was spartan and it was harder to work with these huge yachts. These yachts were created for speed, not comfort, and that was very apparent after a day sitting on the hard deck of the ship! The crew were expected to help prepare food and clean down the yachts, and it was compulsory for everyone to have a go at properly crewing the boats. Part of this included

being hoisted up the mast! Eamon Reyn, our vice-president, told us that being on the racing vessels meant being much closer to the water and was “quite a visceral experience”.

Their journey took the two vessels and their passengers from Auckland to sail around the beautiful islands and bays of the North Island. The weather was idyllic, with the first day being the most challenging day weather-wise. The rest of the week was very calm, easy sailing.

Oceans of Hope’s mission is to change disability to ability and create an atmosphere of understanding and empathy for the unique circumstances that come with being diagnosed with MS. Speaking of the feeling that comes with being on two such prestigious vessels, Munns says:

“Everyone that we pass waves and takes photos ... and generally think that we are awesome for being on these two legendary boats. What’s brilliant is that they don’t know the abilities of everyone on board ... they don’t know how difficult it is for a lot of us to move around and they don’t know our fears. All they see is magnificence.”

Staying Well

Over the winter, infections and colds can really have a massive adverse effect on those with chronic illness. Since both MS and Parkinson's come with decreased mobility, it can make it hard to shift bacterial or viral infections, especially if they move onto the chest. Although it's hard, it's sometimes best to tell those around you to stay away if they have even a small cold or cough. What is inconsequential for them could really set you back.

Influenza becomes more prevalent in winter simply because more people are sharing the same spaces. The flu vaccine becomes available from the 1st April and is still one of the best ways to protect yourself. It takes about two weeks for the vaccine to be fully effective, and protection lasts about six months. The vaccine is funded (usually free) for those with Parkinson's or Multiple Sclerosis and free for anyone 65 and over. Flu vaccinations will be available from your GP practice and some pharmacies; however, it will only be funded at GPs, not pharmacies.

The best defence against infection is – as always – washing your hands! A thorough hand wash is the most effective way to protect yourself against bacterial and viral infections. Here are some quick guidelines from the Department of Health:

1. Wet your hands under clean running water. Use warm water if available.
 2. Put soap on your hands and wash for 20 seconds. Liquid soap is best.
 3. Rub hands together until the soap makes bubbles.
 4. Rub on both sides of both hands ...
 5. in between fingers and thumbs ...
 6. and round and round both hands.
 7. Rinse all the soap off under clean running water.
- Dry your hands all over for 20 seconds. Using a paper towel is best (or a clean, dry towel).

If you're using anti-bacterial gel, use the same hand motions as above to make sure you've cleansed every nook and cranny.

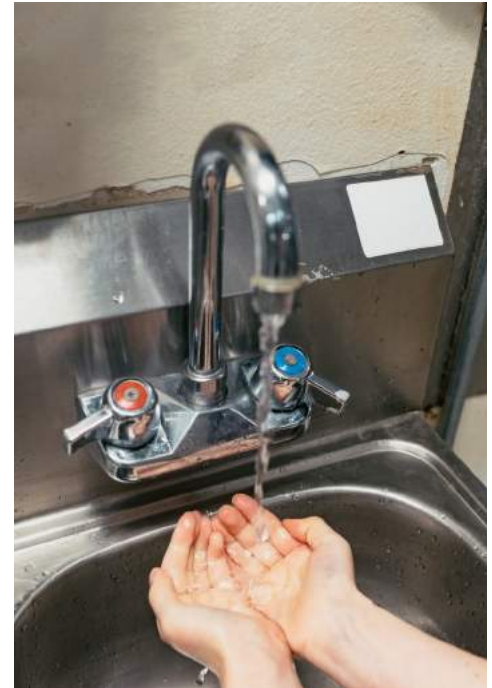
Of course, even if we take all the precautions possible, getting the flu or a cold can still happen.

Following a few, simple guidelines can prevent the spread of infections and help you to get better more quickly.



When coughing or sneezing, do so into the crook of your arm, not into your hands. If you do cough or sneeze into your hands, or blow your nose into a tissue, wash your hands immediately after, as above.

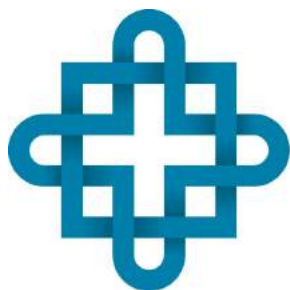
The best defence against infection is washing your hands



Avoid going out to crowded places, especially if it's cold outside. Not only do you not want to spread your germs, but cold weather also puts extra pressure on the respiratory system, which is where the effects of influenza are mainly felt. If you begin to have trouble breathing, or a fever for longer than a day, contact your GP immediately.

Even though you're staying indoors, it's also important to keep active. There are some great exercise programs that can be done in your living room or even your chair. Our physio team can recommend some nice easy exercises that you can do by yourself if you think it'll be hard to get out this winter.

People with Parkinson's and MS are considered high risk, as are people over the age of 65. Infections can also impact on certain treatments for Multiple Sclerosis, so it is important to let your medical team or GP know if you're due for a treatment, or if you think you're not getting better.



New Zealand Brain Research Institute

Genetics Research in Parkinson's

Contributed by Lindsay Daniel, MSPC Member

It used to be thought that genes had no role in Parkinson's, but this notion is changing. The research community is still learning about how our DNA and changes within it contribute to our risk of developing Parkinson's. At NZBRI, we have been collecting DNA from research participants since 2012, and now have samples from more than 300 people with Parkinson's and approximately 60 control participants. We work closely with geneticist Prof. Martin Kennedy

What we know about genes in Parkinson's

A small number (roughly 10%) of Parkinson's cases are considered to be familial - this means they arise from sequence variations (referred to as mutations) in specific genes. The other 90% of cases are considered sporadic or of unknown cause. The current thinking is that these sporadic cases are due to a combination of both genetic and environmental factors (anything not genetic). In these cases, the sequence variations increase risk of an individual developing Parkinson's, but by themselves are not sufficient to cause the disease. These risk variations are not consistently passed on to subsequent generations. Overall, it is likely that an individual has more than one genetic risk factor and is exposed to more than one environmental factor.

Genetic investigations are generally not carried out as part of the standard clinical assessment of Parkinson's. There is little clinical value to knowing an individual's genetic risk of Parkinson's because it is not possible to target treatment based on the genetics of an individual.

GBA

Sequence variations in the GBA gene are some of the most commonly-occurring ones known to increase the risk of Parkinson's. Recent work by PhD student, Oscar Graham, has established that in our local people with Parkinson's, 9.3% possess one or more variations within the GBA gene known to be associated with increased risk of Parkinson's (published Jan 2020 in [Parkinsonism & Related Disorders](#)). This rate is similar to international studies of predominantly European populations. The GBA gene can be technically difficult to study in the lab. Part of Oscar's challenge was perfecting methods and validating them, to ensure the actual gene was being sequenced.

It is important to know that sequence variations in the GBA gene do not in themselves cause Parkinson's; rather they may contribute to the risk of developing it. Most people with GBA gene mutations never develop Parkinson's.

The results of Oscar's GBA work have also contributed significantly to a research paper (currently under review) produced by Assoc. Prof. Justin O'Sullivan and his team from the University of Auckland. This study proposes that GBA may not only increase risk through specific changes in its DNA sequence, but also via interactions with other genes. Oscar's data was able to provide key observations that support their theory. This work identified a network of genes that interact with GBA, and may provide new clues to the biology and genetic factors underlying Parkinson's.

Cont. page 11

Genetics Research in Parkinson's cont.



Why is GBA so important?

The GBA gene encodes the enzyme beta-glucocerebrosidase. This acts as a 'housekeeping' enzyme, helping to break down molecules not needed by the cell. There is some evidence that activity of this enzyme is decreased in all people with Parkinson's (even in the absence of sequence variations) and that interactions between the enzyme activity and alpha-synuclein may be important in the development of Parkinson's-related pathology. There is quite a lot of research underway seeking treatments that might alter the activity of the beta-glucocerebrosidase enzyme and thereby slow down the course of Parkinson's.

Join NZBRI on Facebook

at www.facebook.com/nzbri for up-to-date NZBRI Parkinson's research as well as staff profiles and NZBRI events

Self-help tools

Melon is an app with a health journal, resources and self-awareness tools to help you manage your emotional wellbeing. You can also join their online community to connect with and support wellbeing (Melon Health)

Mentemia is an app that you can use to monitor, manage and improve your mental wellbeing by setting daily goals and tracking your progress (Mentemia)

Staying on Track is an e-therapy course that teaches you practical strategies to cope with the stress and disruption of day-to-day life (Just a Thought)

Working through depression is a personalised online programme that focuses on positivity, lifestyle changes and problem solving (The Journal at Depression.org.nz)

Working through problems with Aunty Dee is a tool to work through problems, generate ideas and find a solution (Le Va)

Parkinson's and the Gut

Studies into Parkinson's have begun to show that there may be a strong correlation between the way the gut functions and the emergence of Parkinson's. The build-up of a protein called alpha-synuclein has been linked to the development of Parkinson's, with two recent studies going further and showing that this process may begin in the digestive system.

Viviane Labrie of the Van Andel Research Institute studied 1.6 million people in Sweden, looking at the correlation between the appendix and the development of Parkinson's. It seems that appendix removal as a young adult can lead to an almost 20 percent lower risk of Parkinson's later in life. Labrie and her team looked at appendixes from people with and without the condition and found the clumps of synuclein protein in the nerve fibres in nearly all of them. Labrie says that this "could act as a seed for the disease in the brain."

Subhash Kulkarni at Johns Hopkins University goes further into looking at why this protein builds up and becomes harmful to the brain. Kulkarni has found that around a third of neurons in the small and large intestine of mice were being lost every seven days. These neurons are "clear[ed] out" by a kind of immune cell called macrophages, which allow stem cells in the gut to replace the lost neurons. Kulkarni says that when his team altered the number of macrophages present or changed the speed at which the neurons in the gut were replaced, this build-up of alpha-synuclein began to occur.

The findings from both these studies have been warmly, if cautiously, received. It is unclear at what creates this imbalance in the first place in humans and what significance these findings will have in future research.



Staff together at our December 2019 planning day
little did we know then that circumstance beyond our control would put some of our plans for 2020 on hold



The Nordic Walking Group enjoying a lovely day at Hagley Park—pre lockdown

Multiple Sclerosis & Parkinson's Canterbury Inc.
49 Sir William Pickering Drive Christchurch—Phone 366 2857—email support@ms-pd.org.nz