Multiple Sclerosis
& Parkinson's
CANTERBURY

strong connections

NEWSLETTER MARCH 2021

President's Message

"How did we get here? How do we find our way through this? And exactly who are we again?"

Tessa Kain and Mungo

These questions, (taken from publicity for comedian Bill Bailey's current tour) couldn't resonate more with our current situation.

With the rest of the world, we are living through extraordinary times where survival, recovery and growth are dependent on our ability to analyse and evolve.

MSPC, along with most businesses and not for profits, has seen its revenue significantly affected by the ramifications of Covid 19 and we are working very hard to find our way through.

I would like to thank our committee for all the work they are continuing to put into this, in particular Ann Morrison (Treasurer) and Ann-Marie Kite, both of whom continue to dedicate huge amounts of time to the cause.

Karla and her team have brought a new energy and a high level of professionalism to our Society and progress is already apparent.

From their fresh perspectives, and from increased member engagement, the team is redefining how we operate and how best to deliver the services our members want and need. For those of you who haven't completed one of our surveys in the past, I urge you to do so at the next opportunity.

It's an exciting time for MSPC. I look forward to seeing you at one of the many events we have planned for the year ahead – onwards and upwards.

Tessa Kain
President

Manager's Message

Karla Gunby

Greetings everyone.

This is our first big newsletter for the year and we will have mini email versions throughout the year. The new team and I have been learning the ropes as fast as we can. We hope to have our support groups and peer support groups up and running across Canterbury as soon as possible. I know that these have been missed.

You may have noticed the slight change in the MSPC logo. This was just a refresh from the old branding. It will help us to use colour and brighten up our material. The website is also going to get a refresh, with a lot more information on it and an ability to pay memberships and register for events.

MS and Parkinson's Canterbury is a membership-based organisation. The board have decided to remove the membership annual renewal date of the 31 March and instead it starts from the date of payment. This means that most of you will be receiving your invoice in March, but if you have just paid in January, you will not be getting another invoice a couple of months later. We hope this suits members better. We are also introducing a 'Support a Member' option, where members can sponsor other members who are not able to afford membership, but still need the services. We hope that we can support more people this way across Canterbury.

If any of your contact information has changed, please let us know on support@ms-pd.org.nz. We are updating our database and this information will help us to stay in touch.

I have come from community development in the Christchurch City Council and before that running disability organisations overseas. I can only see opportunities ahead for this organisation. The team has the potential to have a real impact, but I know that we are in the building phase, after having gone through some real change.

Please ring the nurses or physio if you need some support, this is what they are here for.

Keep well

Karla Gunby
Executive Manager

Thinking of volunteering?

We are looking for additional volunteers. Can you spare a few hours per week?

We are currently seeking volunteers for:

- Reception
- Gym assistants
- Events
  - **Street Appeal** 3 and 4 September 2021
    We need collectors and site coordinators
  - **Bingo Babes Event**
    Saturday 8 May 2021
    We need help with afternoon tea and runners for raffles etc.

Email support@ms-pd.org.nz or call 03 366 2857

Trade Me Fundraising

Can you donate items?

We would appreciate any items valued at over $50 in good or near new condition that you would like gone from your house. Drop them into the office or we could arrange to pick them up if that suited.

Email support@ms-pd.org.nz or call 03 366 2857

Speech and Language Therapist sessions

Available monthly

Did you know we offer speech and language therapy maintenance groups?

You must be a member and have completed some previous speech language therapy (group, one to one sessions, LSVT, VAMP) through the DHB.

Bookings essential. Phone the office on 03 366 2857

Gym sessions

We offer open gym sessions, where you can be supervised by our physiotherapist, Tara, or an exercise therapist to keep you on track and help you get the most out of your session. We will be extending the hours of the gym as the sessions are becoming increasingly popular. We will keep you informed.

There is a gym concession card for members.

Valid for our exercise classes or open gym sessions.

Normally $8 per session or class, concession is $56 for 8 sessions.

The BrainTree project is gathering momentum with key milestones reached:

- Resource consent has been granted by Christchurch City Council
- Building consent has been granted to commence the civil works which are due to be underway this month.
- Armitage Williams has been appointed as head contractor for the project

To find out more about BrainTree and to keep up to date with progress, sign up for the newsletter by emailing:

maddie@canterburybraincollective.org

BrainTree A wellness centre for brain health

Reading Recommendations

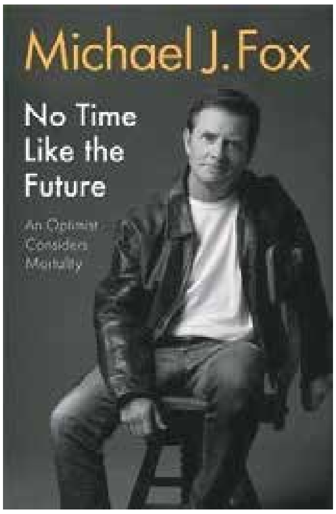
No Time Like the Future

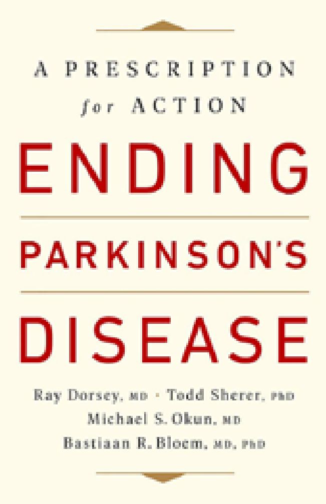
Michael J Fox

Ending Parkinson's Disease

Ray Dorsey, MD, Todd Sherer, PhD
Michael S Okan, MD, Bastiaan R Bloem, MD, PhD

Head to your local library to pick up these great reads





Bingo Babes

Saturday 8 May, 2pm-5pm
Caledonian Society Hall,
5 Michelle Place, Wigram

Tickets $25 (includes 1 bingo card) available from Eventbrite www.eventbrite.co.nz/e/bingo-babes-tickets-142998928645

Bring cash for afternoon tea, extra cards, raffles, chocolate wheel. Limited EFTPOS available.

We still need:

Auction items - do you have a bach you can offer for a weekend getaway? Anything to contribute to a 'Gardening' package? Any other suitable items?

Raffle and Chocolate Wheel prizes - wine, chocolates etc.

Podiatry sessions

Did you know we offer a subsidised podiatry service?

Members only. From 1 April the cost is $30 for a 15-minute appointment at our offices in Sir William Pickering Drive, Burnside.

Bookings essential. Phone the office on 03 366 2857

Update from the Nurses

It has been a busy first few months for us. We've been learning about educational material, research and resources to best support our members. It has been a pleasure getting to know more of our members through visits to the gym and our nursing assessments.

We are also establishing ourselves and connecting with various community agencies to provide options for support and make appropriate referrals to trusted services.

We have several upcoming educational seminars and trainings that will help keep us abreast of the latest information on MS and Parkinson's.

We both attended the Halswell morning tea at the Old Vicarage. The community support groups and morning teas will also provide an opportunity to meet more of our members in Ashburton, Rangiora and Christchurch as the year unfolds.

In the meantime, please call if you require any advice or to schedule a nurse's appointment here at the Society.

Deborah Ballantyne
Registered Nurse

Elspeth McKeon
Registered Nurse

Update from the Physiotherapist

Our open gym sessions are well attended, and we are working on updating some of our class content based on the latest exercise guidelines. We hope to have some new class and gym options available later in the year.

For the next 6 weeks we have Fidelis a physio student working with us. Fidelis will be helping in our gym and classes. Fidelis and I are also available to see members individually to update home exercise programmes and provide advice and support on managing your condition.

Please get in touch if you would like an appointment.

To contact our nurses or physiotherapist, call 03 366 2857

Tara Martin
Neurological Physiotherapist

Robin and his GPS Alarm

Robin England lives with MS and is a regular user of the MS and Parkinson's gym. He lives in Papanui with his wife. When Robin was 70 he went into hospital for a hip operation. This exacerbated his mild undiagnosed symptoms and he went on to get a diagnosis of MS. Robin is now 75 and enjoys keeping fit. However, he realised that he needed an alarm for when he was out and about or if he had a fall at home. He often heads to the races in Westport and Reefton with friends.

Robin discovered that the cost of the alarm could be covered with his disability allowance. Through a contact, he found out about NevaAlone and the GPS beacon. Robin is keen to tell others of the advantage that he got from having Verryn from ADT involved in the process. Robin said "the cool part about it is, Verryn did everything; she came to the home, assisted with the disability allowance application and keeps in touch to monitor the use of the alarm and answer any problems". Robin highly recommends having the alarm and he wears it around his neck. He also likes the fact that the alarm can detect whether it is a fall, been dropped on the floor or has been pressed by the person. He said it is like charging a phone at home and he also has a USB attachment that can be used when he is away or in the car.

Robin encourages his friends and others at the gym to get the most they can out of the disability allowance to help cover expenses. Robin's allowance also covers some medical fees, prescriptions, his lawns being mowed and outside window cleaning.

PHARMAC
TE PĀTAKA WHAIORANGA

PHARMAC MS Drugs

PHARMAC have announced that it will be widening access to all funded multiple sclerosis treatments from 1 March 2021. 1800 people with multiple sclerosis will be able to stay on their treatment for longer, and some who had stopped funded treatment may now be eligible to restart.

Multiple sclerosis is a progressive neurological condition that leads to increasing levels of disability. Jeremy Seed (Kai Tahu/ Kati Mamoe) has had multiple sclerosis for eleven years. The former New Zealand Army officer and father of two is relieved that he will be able to stay on his treatment for longer. “It is really good news. The 500-metre walk was an annual stressor, and I was worried each time I would no longer qualify for my medication. Ironically, stress can exacerbate MS, so not having to worry about it is fantastic,” says Jeremy.

To ensure ongoing eligibility for treatment, people with multiple sclerosis are assessed with the Expanded Disability Status Scale (EDSS). This is a method of quantifying disability in multiple sclerosis and is used to measure and assess disease progression.

PHARMAC’s director of operations Lisa Williams explains, “We wanted to make sure that all those who were benefitting from the funded treatments were able to continue to get them. To support this, we are widening the eligibility criteria to people with an Expanded Disability Status Scale (EDSS) score of 0 (as soon as you are diagnosed and have had two qualifying relapses) to 6.0 (inclusive).”

An EDSS score of 6.0 means that someone can walk 100 metres with or without rest and/or assistance. They can use a cane, crutch or brace. Previously, they would have had to walk 500 metres without rest or assistance to stay on funded treatments.

“People with multiple sclerosis who stopped funded treatment due to the previous eligibility criteria may now be able to restart funded treatment. People should talk to their specialist to work out if that is an option for them.

“PHARMAC is also simplifying the application process for multiple sclerosis treatments,” says Lisa. “Rather than applying to a group of PHARMAC appointed clinical experts, clinicians will now use the standard electronic Special Authority process. This will make it quicker for people with multiple sclerosis to access funding for the medicine they need and less burdensome for clinicians to apply.”

Multiple Sclerosis New Zealand is pleased to see the changes to the Special Authority. “We have been advocating for these changes that will keep people on treatment for longer, thereby improving their brain-health, keeping them in work longer, active, and able to support their families and themselves. These changes will also help to speed up the approval process and relieve the pressure on New Zealand’s under-resourced neurology workforce,” says Multiple Sclerosis NZ National Manager Amanda Rose.

Having recently retired from the New Zealand Army, Jeremy now works for the Returned Services Association (RSA), supporting current and former military personnel and their families. “Being able to stay on my treatment means I can focus on the things that matter – my family first and foremost, and my new role with the RSA.”

(Media Release - 12 February 2021 - Released by PHARMAC)

To tell or not to tell that is the question!

By Sue (member with Parkinson’s)

One of the first discussions my husband and I had following my Parkinson’s diagnosis, was how soon to tell people, especially at work.

Being a very private person, his take was “you don’t have to rush into telling people”.

I thought about this for a nano-second – yes, I can be very decisive when I want to be – and my thoughts went something like this.

I have worked with my team for seven years now, they are like my second family. As a team we have supported each other through happy times, difficult times (COVID springs to mind) and personal tragedies.

I have never felt judged or isolated from my team and I don’t want to start now. So, if I fumble for words sometimes, I have a day where I am tired, stressed – my job does that to me anyway – they know it could be “Parkies” playing up and misbehaving.

We even joke about it sometimes and that helps. I’ve tried getting out of things at work, “sorry, I’ve got a condition” but it doesn’t wash, and you know, I’m glad! I’m glad that after the initial shock of sharing my diagnosis, my work friends still give me cheek, still value my work and treat me as me, not a person attached to a diagnosis.

One day I admit I was feeling a bit sorry for myself and a close friend at work told me off, reminding me that Parkies can’t be allowed to take over my life and there is much joy to still be had in life. If life becomes swallowed up by Parkies that is the last thing I want.

Life has its challenges, but that’s nothing new. It is how I face up to those challenges that make the difference, I am not Parkies and Parkies is not me! I am still me and I intend to continue to find the joy in life, love and family and I am determined that nothing can take that from me.

Follow Sue’s Blog here:

www.parkiesandme.wordpress.com/blog/

Multiple Sclerosis
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New Zealand
Brain Research
Institute

April is Parkinson's Awareness Month

This year Multiple Sclerosis and Parkinson's Canterbury are joining forces with the New Zealand Brain Research Institute to celebrate Parkinson's Awareness Month. We'll be holding two seminars (they'll be identical) at the

Te Hāpua: Halswell Centre, 341 Halswell Road, Halswell.
Monday 12th April at 10.30am and Tuesday 13th April at 5.30pm

The Brain Research Institute will be releasing some of their new research results and we hope to see you there.

Registrations essential www.nzbri.org/Events/

Are you interested in helping further research into Parkinson's disease?

The New Zealand Brain Research Institute have one of the longest running Parkinson's studies in the world, and they're based right here in Canterbury. To ensure the research is thorough they also use healthy people of similar ages to the participants with Parkinson's disease for comparison.

They are currently looking for both males and females who are between the ages of 56 and 72, without Parkinson's, to match current participants. They have various projects, some are one offs and others are more long term. There will be some reimbursement for your travel costs.

Please contact Leslie Livingston on 928 1330 if you would like more information on how you can make a difference.

MS talk

Dr Ruth Leadbetter is a Wellington based neurologist who is particularly interested in neuroimmunology, which covers neurological conditions believed to be caused by dysfunction of the immune system, such as multiple sclerosis (MS).

She is currently working with the New Zealand Brain Research Institute on a research project studying multiple sclerosis. There is a lack of MS mortality data worldwide and there have been no nationwide studies on MS mortality in the southern hemisphere in over 50 years. This study will assess MS mortality rates in New Zealand and investigate potential contributing factors.

Ruth's results will provide essential baseline information for treatment funding decisions and other healthcare initiatives needed to improve the survival of New Zealanders with MS.

Later this year she will present her findings to the members of MS & Parkinson's Canterbury. Further details to follow.

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