



**Multiple Sclerosis
& Parkinson's**
CANTERBURY
strong connections

strong connections

NEWSLETTER August 2021



President's report

At our recent AGM we farewelled Tessa Kain as President of the Society. Through dedication and determination, Tessa has guided the Society through difficult times, placing us in a positive position for the future. A high standard of service delivery and professionalism was at the heart of her presidency and we thank her for her foresight and commitment. Tessa also represented MS and Parkinson's on the Board of the BrainTree Wellness Centre and worked hard with Simon Challies and the Directors of Canterbury Brain Collective to bring us our future home and a wonderful asset for those with neurological conditions.

As the incoming president, I look forward to working with the Committee and building on these initiatives by consolidating our funding, supporting our team with the development of additional services and broadening our reach to those in Canterbury with MS & Parkinson's.

New to our Committee is Rachel Teahen of Nexia NZ, who will take on the role of Treasurer. We are fortunate to have Ann Morrison stay on the Committee as Vice President. Ann has done a sterling job serving the Society as Treasurer for several years.

Thank you to everyone who has volunteered to support our Annual Appeal and I look forward to meeting many of you at our forthcoming morning teas.

Anne-Marie Kite
President

Manager's Message

Greetings everyone,

This last quarter has been one of consolidation. The new team seems to be bedded in now and we are making progress with all of our systems. The lead up to the street appeal shows us how much the Society depends on members and volunteers to support us. It has been great seeing people rock up to the office and say they are willing to collect for us again this year!

I will be attending the MS Conference in October in Wellington and this will be an opportunity to get together with managers from around the country to discuss programmes and services.

Keep well

Karla Gunby

Executive Manager

The many faces of MS & Parkinson's

Keep an eye out on Facebook for our new fundraising awareness campaign we are running on social media.

We're using a series of images (above) to draw attention to the many statistics associated with Multiple Sclerosis and Parkinson's disease in New Zealand - and to remind everyone that our organisation is self-funding and relies on public financial support to continue our essential work.

Annual General Meeting

July 2021

At the AGM the President Tessa Kain was pleased to report that as a result of our organisational review and restructure, the Society is in an improved financial position and firmly on track to meet its strategic objectives.

Under the leadership of our Executive Manager, Karla Gunby and her professional team, we have increased our services, reduced waiting lists and expanded our educational opportunities. Along with greatly improved communications and engagement with members and stakeholders, we have increased our funding prospects and developed stronger relationships with the Ministry of Health and CDHB, along with other neurological community providers.

The Committee was delighted to recognise Dawn Baker and elect her to Life Membership of the Society. Dawn has served on the Committee for eight years, with five of those as Vice President. We will miss Dawn's experience, wisdom and 'editing skills' on the Committee and we are grateful that she is on hand for any on-going advice and has agreed to be a member of our Feedback Group. Dawn was presented with her certificate, plaque and flowers.

Tessa was recognised and thanked for her hard work and dedication as President and presented with a bouquet of flowers.

The AGM ended with guest Peter Orpin of Lane Neave speaking on the governance of modern charities. This is a pertinent topic as the Committee reviews our governance structure as we move to extend our services and be landowners and future landlords of the BrainTree Wellness Centre.

The Committee for 2021-2022

President: Anne-Marie Kite

Vice President: Ann Morrison

Treasurer: Rachel Teahen

Committee Members: Malcolm Rickerby and Ingrid Robertson



View the 2020/21
Annual Report
on our website:
www.ms-pd.org.nz



Mungo

Many of you have met Mungo, our 15 ½ year old border terrier mascot. Along with our outgoing president, Tessa Kain, he is moving on to his next challenge. We thought you might enjoy one last dose of cuteness.



BrainTree Wellness Centre Progress Report

The building:

July has seen major progress on site with the installation of the super structure - concrete walls and structural steel framing. Exterior wall framing is underway and is expected to be completed by 18 August.

Funding:

This is on track with grant applications, community groups donations, anchor donors and private donors.

Fundraiser:

Smith's City Golfing with the Stars Tournament will be a major fundraiser. This is scheduled for Friday 8 October 2021.

Recruitment of a BrainTree Centre Manager:

This is a crucial part-time position to manage the day to day running of the Centre, stakeholder engagement and funding, and property management, including tenancies, leasing, and maintenance.

Operational progress:

Potential tenants are presently being formally approached. Fit out and furnishings of the building have been decided.

BrainTree vehicles:

Dougal and the team at Gary Cockram have kitted us out with a car and van, the latest Hyundai models. These will be available for organisations at the Centre.

To stay up to date with the project go to www.canterburybraincollective.org



BrainTree A wellness centre for brain health

Keep track of your medications

Have you thought about having an app on your phone that could help you keep track of your medications? For example:

Medisafe Meds and Pill Reminder.

Its features are:

- Medicine list with shape and colour identification feature
- Medicine tracking history
- Medicine reminders and alerts
- Repeat or refill reminder
- Notifications can be shared with other people
- Reports can be generated for sharing
- Can include measurements such as blood pressure, blood test results, pain scores, mood, weight and temperature or general notes

The basic features are free and it is available on Apple and Android. While it is US based, you can add in the NZ meds to customise it to you.

Have a think about what works best for you.

The Society's 60th Anniversary

Next year is our 60th anniversary and as we move into BrainTree, it will be something to celebrate. Have you seen something that worked well somewhere else, or do you have an idea that could showcase our 60th anniversary?

Would anyone like to join a working group to go through ideas and help make a plan? This is something that we will be looking for funding for, to help with the process.

We would love to hear from you. Contact Karla on 366 2857 or manager@ms-pd.org.nz.

Have you thought about starting at a Gym?

Speak to Tara our Physiotherapist or Lee our Exercise Therapist, to help you create a tailored exercise programme to use at our gym, your local gym or at home.

Sessions at our gym in Burnside are:

- Monday 1pm to 3pm
- Wednesday 1pm to 3pm
- Friday 10am to 12pm

Safe Driving with MS or Parkinson's

Age Concern Canterbury, in conjunction with MS and Parkinson's Canterbury, will be running a series of safe driving workshops.

Please contact Kirsty on 03 3662857 or email support@md-pd.org.nz to register your interest.

Wednesday 20th October
Rangiora (venue TBC) 10:30am – midday.

Further dates are to be confirmed.



Safe Driving Tips



D

Don't drive

if you feel tired, lightheaded or stressed. Always wear your seatbelt



R

Remove distractions

in the vehicle. The use of devices, conversations with passengers and eating can all divert a driver's attention



I

Increase the awareness

of your surroundings by frequently checking mirrors, particularly while changing lanes



V

Verify you are driving

at the correct speed limit. Keep a safe distance from the car ahead of you to allow time to brake safely



E

Exercise caution

when emergency vehicles approach. They have the right of way. Watch for flashing lights and listen for sirens



Peer Support Groups and Workshops

We have steadily been increasing our peer support groups and workshops for our MS & Parkinson's members and have been delighted to see so many of you maximising the opportunity to connect with one another. Research shows us that peer support really can improve people's wellbeing, especially as it can help to talk to like-minded individuals about what it's like to live and thrive with specific conditions.

We have a wide range of peer support groups, morning/afternoon teas and educational workshops in the pipeline, across various locations and we are adding to these all the time.

We have listed those that are upcoming and warmly invite you to take a look on our website and Facebook page to keep up to date with any that we add.

We kindly ask that you RSVP for these events so that we have an accurate idea of numbers attending. If you have any questions or suggestions please do not hesitate to contact us.

DATES FOR YOUR DIARY:

Upcoming MS Peer Support Groups

Thursday 23rd September, 5.30pm – 7pm
MS & Parkinson's offices. With Guest Speaker Jess Deacon, CDHB MS Nurse

Thursday 4th November, 5.30pm – 7pm
MS & Parkinson's offices. Guest Speaker TBA

Thursday 16th December, 5.30pm – 7pm
MS & Parkinson's offices. End of Year Social Catch Up

Young Onset Parkinson's Peer Support Groups

Wednesday 25th August, 4.30pm – 6pm
MS & Parkinson's offices. With Guest Speaker and Member Sue Waight

Wednesday 6th October, 4.30pm – 6pm
MS & Parkinson's offices

Wednesday 17th October, 4.30pm – 6pm
MS & Parkinson's offices

Rangiora Morning Teas for both MS & Parkinson's Members

Thursday 23rd September, 10:30am

Black and White, Rangiora with Lesley Williams

Wednesday 10th November, 10:30am

Rangiora - Knox Church with Lesley Campbell from Lifelinks

Ashburton Morning/Afternoon Teas:

Wednesday 25th August, 1.30pm

Hospice Mid Canterbury with Lesley Campbell from Lifelinks

Parkinson's Spouse/Carers' Group with Facilitator Gaynor Morris

Tuesday 21st September, 10.30am

Bridgettes, Aikmans Road by Merivale Mall

Thursday 21st October, 10.30am

Strange Bandit, 175 Roydvale Avenue

Tuesday 16th November, 10.30am

Ilex Café, Botanic Gardens, Central City

Thursday 16th December, 10.30am

Papanui Club, 310 Sawyers Arms Road, Bishopdale

Educational Workshops for both MS & Parkinson's Members

We are just in the process of organising dates for our series of Educational Workshops, starting with our Safe Driving workshop facilitated by Age Concern, on **Tuesday 24th August**.

Other educational topics will include presentations from MSD on available benefits and services, navigating public transport with the team from Environment Canterbury, cycling safety and stress free riding, Lifelinks and more!

Bookings are essential for these workshops as we are strictly restricted in numbers. If workshops get booked up we will look at adding more dates



Communication Maintenance and Voice Practice

Did you know we have a Parkinson's Communication Maintenance and Voice Practice Group that meets at the Society each month?

The aim of the group is help members 'use not lose' their communication and voice skills. It can also help maintain swallowing safety and the enjoyment of eating and drinking, in order to live well with Parkinson's.

If you have done a VAMP or LSVT course with the CDHB out at Burwood, then you will already have the tools to help you. This group is a good motivator to encourage you to keep up those skills.

Kirstie Koller is the experienced Speech Language Therapist who runs the class. It is free for members.

Morning tea is provided and partners/carers are welcome to attend.

Groups run on the last Thursday of the month – 26 August, 30 September, 28 October, 25 November.

Call our office on 03 366 2857 to book.

Voice Practice: 9.45am to 10.15am
(LSVT / VAMP graduates)

Communication Group: 10.30 to 11.30am



Tips and Resources

Parkinson's:

www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-Health-at-Home

full of great resources, classes, education etc.

Multiple Sclerosis:

Enrol in "Understanding Multiple Sclerosis" here www.ms.mooc.utas.edu.au/ Registrations are now open for September and it's free.

Kiss goodbye to MS - NZ Facebook page here: www.facebook.com/KissgoodbyetoMSNewZealand

Annual Street Appeal

Can you spare 2 hours to help us on Friday 3rd or Saturday 4th of September with our annual street appeal? We are still looking for 120 collection volunteers and site coordinators in all areas of Canterbury.

Please call Bridget on 03 366 2857 or email fundraiser@ms-pd.org.nz.



Do you want to remain independent?

Whether you're at home, at the shops or on holiday, we can help you with that!

NevaAlone GPS Mobile Medical Alarm

Completely mobile, lightweight and convenient, it's wearable as a pendant or belt clip, has a fall detector and has GPS tracking. It's also water resistant with two way voice communication and is WINZ/MSD accredited.

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Navigating Care

The staff and I have been discussing our model of care and were looking at a recent paper titled Personalised Care Management for Persons with Parkinson's Disease, September 2020, from researchers in the UK and the Netherlands.

It talks about the growing awareness of the delivery of an integrated and personalised care plan and how necessary it is to meet the needs of people living with Parkinson's.

The link to the full article is here:

www.ncbi.nlm.nih.gov/pmc/articles/PMC7592650

As you already know, a diagnosis of MS or Parkinson's is a lifechanging experience. It's important to feel like you are in the driver's seat. Gathering a good team of supporters around you will make you feel more confident. Team members include your family and friends, your GP and neurologist, the Society's nurse and physio, peer-to-peer support group members, gym class members, coffee group members, etc.

The diagram here shows the layers of health care. The Society's services and support can assist with the top three layers and help make those connections – self management, peer-to-peer support and allied health professionals (our physiotherapist and nurses).

The health care system has many complexities. Different teams may be relevant at different times and they may overlap. For example the DHB in-patient team when you are in hospital vs the primary care team with your GP vs the community team to help you maintain your condition.

The staff at the society are an advocate for the other levels of care and we are here to help you navigate through the health care system and the different layers of support.



Keeping in touch with your team when you need them is vital to ensuring you stay at your best and feel in control of your health.

Karla Gunby and the Clinical team – Deb Ballantyne, Elspeth McKeon and Tara Martin



Karla Gunby
Executive Manager



Deborah Ballantyne
Registered Nurse



Elsbeth McKeon
Registered Nurse



Tara Martin
Neurological Physiotherapist

Charity Golf

Our annual Charity Golf event is on Friday 29 October at Clearwater Golf Club, starting at 1pm. We are looking for sponsorship, auction items and raffle prizes. Can you help? We are also taking team registrations at \$795 + GST for a team of 4. Please contact Bridget on 03 366 2857 or email fundraiser@ms-pd.org.nz



Physio update – Tara Martin

My focus for the last few months has been the launch of our Parkinson's Exercise Accreditation and Endorsement Programme. This has been a substantial project for us and we are excited to get this underway.

Through greater and more robust connections with exercise providers we hope Canterbury can be a leader in providing high-quality evidence-based exercise programmes for people with Parkinson's. People can access exercise classes in their local community, as well as the Society continuing to provide these options at our gym.

I've been reviewing the most up to date research in the area and similar great initiatives are already underway in the US. From this we anticipate building a great network of professionals to lead NZ in providing exercise for people with neurological conditions. For more information see www.ms-pd.org.nz/accreditation/

In September and October I will be having 1:1 clinics in Ashburton and Rangiora and continuing to provide appointments here at the Society.

Call the office on 03 366 2857 if you'd like an appointment.

The Hāpai Access Card Making access easier for you

We know that for the 23% of Kiwis who have a disability, everyday activities like shopping, using transportation and engaging with services can be a challenge. This is why the Hāpai Access Card has launched in New Zealand - to greatly improve the customer experience of disabled people and reduce barriers to accessibility in the community.

The card provides a simple way for businesses and councils to know and respond to accessibility barriers. It translates the challenges a cardholder faces into symbols, which informs businesses quickly and discreetly about the support they need. This means people do not have to go into a lot of personal detail to get good customer service.

The businesses who accept the card are trained to respond and adapt to cardholders needs. Many of them also offer discounts as well as concessions, where a disabled person might need an essential companion as well as improved accessibility.

The cost is \$30 and the card is valid for three years. The society can assist you in applying for one by validating your barriers or go to hapaiaccesscard.org.nz.

Call the office on 03 366 2857 to find out more information.



Multiple Sclerosis & Parkinson's

CANTERBURY

Multiple Sclerosis & Parkinson's Society of Canterbury

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Email: support@ms-pd.org.nz

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Ann Morrison - Vice President

Rachel Teahen - Treasurer

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Ingrid Robertson, Malcolm Rickerby

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