



Empowering the movement disorder community

Connect

In every issue:

- 3 Move that BODY!
- 4 Ask our Neuro Physiotherapist
- 5 Ask our Mental Health Nurse
- 16 At your Leisure
- 20 Research

DAILY LIVING HACKS

Learn tips and tricks from the movement disorder community that can make life easier. **Pages 6 & 7**

DRIVING WITH A MOVEMENT DISORDER

Absolutely a difficult topic. Know when to stop and what supports are available. **Page 8**

DANCING WITH A MOVEMENT DISORDER

The story, the research and how to take part! **Page 13**

RIGID RIDERS

Profile on the initiative to get people with Parkinson's cycling!
Page 10

BRAIN CONNECTIONS IN PARKINSON'S DISEASE

Read about the exciting research happening in the Chen Lab **page 17** and hear from research participants **page 19**

SPRING/SUMMER 2022

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Welcome back readers and welcome new readers!

We introduced our 1st issue of *MDC Connections* in the Winter of 2021. It quickly gained popularity and readership, with many positive accolades. We created seasonal issues focused on resources and relatable stories. We are proud of each issue! As we continue on our journey to grow, to inspire and empower the movement disorders community, we have decided to close the chapter on *MDC Connections* and bring you something a little different. Introducing *Connect* giving you more tangible tips, community resources and things you can do now! *Connect* will still bring you stories, resources and inspiration in the same familiar tone and colourful eye candy :) but will be broader in scope and a slightly shorter read.

We hope you continue to take the time to savor each edition and let us know what you like and what could be improved. We are excited to embrace change and growth. You can expect *Connect* will morph again as the seasons change and we try our best to flow with you, our courageous audience.

We invite you to have your say and contribute to *Connect*. Email us at movementdisorders@uhn.ca

Julie
 Editor

Please note that the listings in this publication include events not organized by the Movement Disorders Clinic, the Integrated Movement Disorders Program, the University Health Network, and organizations with which they are not affiliated. Any listing of third-party events or programs should not be considered an endorsement. We cannot be held responsible or liable for any loss or damage suffered as a result of participation in third-party events and programs.

Connect is a collaborative effort by the Movement Disorders Clinic staff, the Integrated Movement Disorders Program, the Patient Advisory Board, and patient contributors.

Supported by the Edmond J. Safra Program in Parkinson's Disease

Move that BODY

The following activities are here to inspire you to move more and get out of your comfort zone. We suggest trying anything that's within your activity level and seems reasonable to do!



Aerobic

[10-min. Feel good morning workout](#)



Strength

[30-min. Weight training for beginners](#)



Balance

[23-min. Standing balance for beginners](#)



Flexibility

[11-min. Full body stretch](#)



Ask our Neuro Physiotherapist

By Haseel Bhatt, PT

Q: "I currently go to the gym but I'm starting to struggle with household chores. Activities such as mowing the lawn are proving more and more difficult. What can I do to build strength so I can continue to take care of my home?"

A: Integrating functional training into your workout routine can be very helpful. For example, if you are having difficulty starting the lawn mower, you may want to consider adding a few 'pulling' based exercises to your routine (see exercise 1 and 2). An exercise such as rowing is not only a great aerobic exercise (which has shown to provide several benefits for people living with a movement disorder) but can also help 'groove' or 'train' movement patterns that are proving difficult and affecting daily activities. In the third exercise, we see that the person is engaging in a full-body strengthening exercise to replicate the demands of pushing a lawn mower.

By adding a few functional exercises to your routine, you can make your workouts more meaningful.

Have a question for Haseel? Email us at movementdisorders@uhn.ca

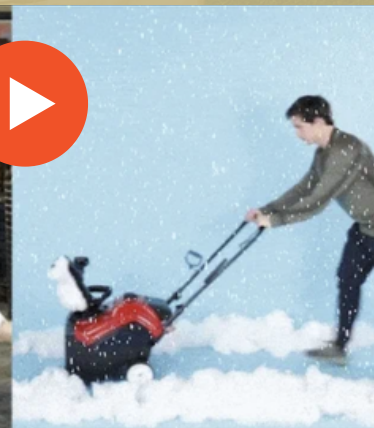
The statements above do not replace specific advice from your health care provider.



Pulley Exercise 1: Rowing Machine



Pulley Exercise 2: Single arm cable row exercise



Pushing Exercise 3: Sled push exercise to replicate the demands of pushing a lawn mower

Ask our Mental Health Nurse

By Keschey Marcelle, RN

Q: I want to develop healthy daily habits, are there tools that can help?

A: When I think about building healthy habits into my daily routine, I think of nourishing my mind, body and spirit. What better way to do so than daily connection with nature. Whether you live in the city, suburbs or rural, find a way to connect with nature on a daily basis. It can mean five minutes sitting in the park feeling the earth, taking a walk along a trail, birdwatching, or tending to a garden or balcony plants. Taking time to be present can be one of the healthy daily habits you develop, and nature can be the tool you use.

Apps can help support healthy habit building. Two of the apps I recommend, that I use, and that I've received positive feedback from patients are *Prana Breath* and *Calm*.

If you have trouble remembering to take your medications, *Medisafe* is highly recommended by members of our Patient Advisory Board.

Have a question for Keschey? Email us at movementdisorders@uhn.ca



Further Reading:

PaRx Launches in Ontario

*"Family doctors need many tools to manage different medical conditions, and **nature prescriptions** are a powerful treatment option."*



Prana Breath

Prana Breath is a calming breathing and meditation app that uses short, simple and doable breathing techniques. It can help with anxiety, concentration and sleep.

Free with in-app purchases



Calm

Calm is an app for sleep and meditation. It's "for anyone who needs a mental break, a soothing sound, or a peaceful night's rest."

Try their "**Daily Move**" videos - 5 minute sessions to gently wake up your body.

Free with in-app purchases



Medisafe

Medisafe is a medication management app to keep you on-track with medication dosing schedules. Receive reminders for each dose and know when your prescriptions are running low. You can also download and email progress reports.

Free

Daily Living Hacks

Living well with a movement disorder can be done. A little effort, motivation and inspiration can go a long way! We've gathered resources full of strategies and hacks to help you continue to do the things you like to do.

Parkinson's

Every Victory Counts Manual - Davis Phinney Foundation

For information and inspiration to live well with Parkinson's.

Staying Independent - Stanford Medicine

Curated publications and articles for staying independent with Parkinson's.

PSP, CBD & Other Atypical Disorders

A Guide for People Living With PSP, CBD, and Other Atypical Parkinsonian Disorders - CUREPSP

Read an Occupational Therapist's take in Adapting to Adaptability page 57.

Dystonia

Living with Dystonia - Dystonia Medical Research Foundation

Suggestions for living well with dystonia.

Tremor

Coping Tips for Everyday Living- Essential Tremor Foundation

Helpful tips to make tasks easier.

Occupational Therapy

Find an Occupational Therapist (OT) - OSOT

Find an OT by location, practice (neurological diseases), services and age group.

Local Health Integrate Networks (LHINs)

Before you explore private OT services, feel free to contact the LHINs about an assessment and services you may be eligible for under government covered care.

Care Partners

15 Ways to Practice Self Care - Parkinson's Foundation

Actionable ways to practice self care. (Applicable for all movement disorders.)

YOUR Daily Living Hacks

Here are a few tips and tricks written by our readers to share and inspire others to live well with a movement disorder.

1

Elimination, and specifically constipation, can be a real problem. I've found a daily bowl of yogurt and kefir with a few dried prunes and a tablespoon of psyllium husks (plus other fruits and nuts of your choice) has made a difference. My hack, though, is a piece of furniture we call the squatty potty. It's a foot stool (excuse the pun) shaped to wrap around the front and sides of your toilet so that when you put your feet on the stool you are in a squat position. This creates enough pressure (pressure you don't want to force yourself) to start and see to completion a full bowel movement. I know it might sound silly, but try it and you will see.

2

Get a dog. A rescue if possible that needs to walk and run every day. They force you to exercise, and for me that 45 minute dog walk every morning is my favourite time of day. I know for some it's not an option but if you can I highly recommend it. The return on the investment is considerable.

3

I have a lot trouble with **handwriting**. It's become small and virtually illegible. Those times when I need to fill out forms or applications by hand become stressful and irritating. I stumbled on a hack that, with practice, can help quite dramatically. Instead of writing (we're talking printing of course) letters of the alphabet starting from the top, try starting from the bottom of each letter. It takes practice and is slow at first but the difference is remarkable. Neuroplasticity at it's finest. Like I say, it's slow at first but legible, if you put in the time it'll pay off.

4

Here's one for that helps me manage **pain and dissociation**: box breathing.

"Box breathing can help you slow down your breathing. It works by distracting your mind as you count to four, calming your nervous system, and decreasing stress in your body."

Box Breathing Steps:

1. Breathe in counting to 4 slowly.
2. Hold your breath for 4 seconds.
3. Slowly exhale through your mouth for 4 seconds.
4. Repeat steps 1 to 3 until you feel re-centered.

Do YOU have any tips for this reader's question?

"I prefer to use an electric toothbrush but my tremor can make it challenging (as it can my regular brush) at times. Has technology provided a solution? Is there a tremor off-setting toothbrush out there somewhere? A wish, not a hack, but worth the ask."

Email your hacks to movementdisorders@uhn.ca

Driving with a Movement Disorder

Written by Linda Redford

Sooner or later, as we age, we all have to face the question: "when is it time to stop driving?" This is a very difficult decision for anyone to make. We all associate driving with personal independence and freedom. I have learned over the 23 years since my husband was diagnosed with Parkinson's disease that it is helpful to consider difficult decisions sooner rather than later. It helps me to prepare and understand possible consequences long before the decision becomes a crisis.

The emotional desire to keep driving can dominate our decision.

Keschey Marcelle, Mental Health Nurse, weighs in: *"A decision to stop driving is an emotional one as it holds meaning to identity and independence. Even when individuals notice their skills are diminishing and their confidence has decreased on the road, fear of isolation and loss of independence leads to their continuing to drive. Driving has been a big part of daily living for many of us and to give that up is considered a significant loss. The question of 'when is it time to stop driving?' really boils down to safety. It is important to have the physical, mental and emotional ability to manage the complex task of driving."*



Research findings identify that people with Parkinson's (PWP) are less safe than non-Parkinson's drivers.

Here are some of the changes to watch for:

- Longer reaction times,
- Problems shifting feet between pedals,
- Difficulties with lane changing,
- Checking 'blind spots' due to neck and upper body stiffness,
- Reduced steering accuracy,
- Responding to light changes due to vision impairments,
- Difficulties parking and/or reversing,
- Inability to break suddenly due to muscle cramping or leg edema from medications,
- Slower judgement and decision-making,
- Excessive daytime sleepiness due to disease or medications.

The emotional desire to remain independent often dominates our thinking when we should be considering the practical process of continuing to do something we have done for 40 years or more, every single day. But, as safety increasingly becomes a concern, options for alternate transportation need to be explored. Talking with family, friends and your family doctor can help make the emotional shift to put safety first.

Driving is a complex task.

Driving is a complex task that requires you to be aware at all times and be able to respond quickly to constantly changing circumstances. If you have received a diagnosis of Parkinson's disease or other movement disorder, then you should be aware of how the disease will affect your driving ability as time unfolds.

Tell your doctor if you or people close to you are concerned about your driving and why. He or she can go over your medical conditions and medications to see if there are treatable problems that may be contributing to driving difficulties. Vision and memory tests are important.

Transportation options

- Public transportation
- Taxi
- Uber/Lyft
- Wheeltrans
- Red Cross
- Compassion Transportation Service
- CANES Community Care
- Carefirst
- Woodgreen
- Sprint Senior Care

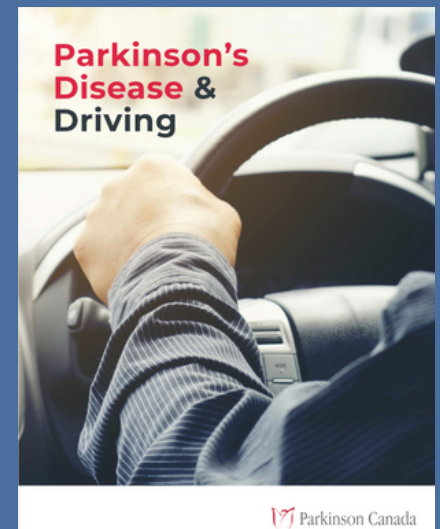


There are many other options. There are also services for needs like grocery delivery. Try searching thehealthline.ca for services you need, in your area.

Driving Resources

Giving up driving is absolutely a difficult decision.

Parkinson's Disease and Driving published by Parkinson Canada provides an assessment checklist, guidelines for talking to the driver who has been diagnosed with Parkinson's disease and research findings.



Hear from an Occupational Therapist about Parkinson's Disease and Driving.

****This webinar is applicable to other movement disorders.***



Rigid Riders

WE GO HARD!

BY STEVEN ISEMAN

4 years ago, when I was about 5 years into my young-onset Parkinson's disease (YOPD) diagnosis, I was working out in a Parkinson's disease (PD) fitness program and paused to watch a friend struggling with a leg strength maneuver. She gave up, bemoaning that PD had made her too weak to continue. I convinced her that her difficulties seemed balance related, not strength, and that it was not as big a limitation as she perceived. She was scared to try, believing that she might fall. We reworked the maneuver so that falling was no longer an issue, and she was instantly successful. She was elated. I saw how fear was acrippler of people living with PD, but that it could be managed. I started to focus on that – looking for signs of unwarranted fear, and assisting with encouragement and support. I found that people responded well and, when appropriately motivated, they could find their extra gear. Even better, I saw that it made them happy.

I took this idea and set up the Rigid Riders cycling team with my friend Mike Loghrin. We were actively looking for reluctant cyclists who had the ability to cycle, but were held back by unwarranted fear.

"Something magical happens when we gather. The pains, fears and limitations that bedevil us in solitude seem to evaporate when we see those around us, with the same issues, working hard, trying their hardest and having fun."

Our pitch was: what if we could make the perfect day to try cycling again; arranged training and logistics so that they felt safe and supported. We formed a team around these goals. When it came to naming our group, we wanted to reflect our attitude of defiance in the face of hardship, so we call ourselves the "Rigid Riders", which is an irreverent taunt to a menacing PD symptom of muscle rigidity. To hammer the point home, our slogan is "We go hard".

Our team has grown each year, but not without great effort. We know how PD can attack our motivation as mercilessly as our bodies, so we have to work that much harder to keep our members engaged and happy. Luckily, something magical happens when we gather. The pains, fears and limitations that bedevil us in solitude seem to evaporate when we see those around us, with the same issues, working hard, trying their hardest and having fun. It is elevating.



Rigid Riders GTA team

"The Rigid Riders is a group of people living with Parkinson's disease (PWP) who have chosen to fight back against this illness."

We all have good days and bad days, and sometimes we may need to draw support from the group, while other times we may be the champion, digging deeper, overcoming unjustified fears, focusing on what you can do rather than what you can't.

The Rigid Riders can help.

The Rigid Riders is a group of people living with Parkinson's disease (PWP) who have chosen to fight back against this illness. We are not content with losing cherished abilities; we are not interested in relinquishing our independence and dignity; and, we do not believe that we are without options in our own health and happiness.

We cycle. Cycling has health benefits for PWP. We believe that intense exercise can be strong and effective medicine for your mind, body and spirit. We also think that cycling can be one of the most effective ways to deliver these health benefits.

Come join us

Just deciding to connect with us is a powerful affirmation - to yourself and to those around you - that when it comes to living with PD you have the will, the resolve, and even a plan to get the most out of the years ahead of you.

Our members cover the full range of cycling abilities and many of us have not cycled since we were kids. Our purpose is to foster a supportive community for all PWPs that have the strength of will to try. And for those that are already strong cyclists, you will also find your place with us. We are a community, a source of inspiration and a movement.

Our goal

Each Summer we complete a 40-kilometer route. In preparation, we train as a team, including indoor spin classes through the Winter and outdoor cycling routes in the Spring and Summer. Spouses and/or care partners are encouraged to attend with you. To help us prepare for our event, we have the support and commitment of some exceptional people, who will help with cycling skills and body preparation to get us limber, psyched and ready for the big day. We have volunteer coaches, who either have an expertise in the rehabilitation of people with movement disorders, or talented at teaching and motivation, or both.

Our training is currently most active in the GTA.

To find out more or to inquire about joining the team, email Steven Iseman & Mike Loghrin at gorigidriders@gmail.com

PEOPLE LIVING WITH PARKINSON'S DISEASE OFTEN WITHDRAW FROM REGULAR EXERCISE FOR A NUMBER OF REASONS:

- **No time:** Make the time. You are experiencing change and you must adapt.
- **Fear of pain or injury:** It will hurt more if you don't move. Exercise can help with muscle rigidity, balance, and flexibility.
- **It's too expensive:** We charge nothing to join. We help with training and volunteer coaching. Everything is volunteer based.
- **No one to exercise with:** We are a supportive team, and we understand what you are going through.
- **Just not motivated:** PD can subdue your motivation. We motivate each other. We build skills together, we celebrate our successes, and we surround ourselves with champions.



A Cross Canada Parkinson's Journey
www.spinningwheelstour.ca

Canada is home to over
 100,000 people living with
 Parkinson's disease.

Starting in June 2022, we aim to cross our big country by bicycle to meet as many people as possible to personally deliver this message: "get moving to stay moving". PD Riders will be Steven Iseman and Jim Redmond, joined by occasional riders.

We start in Victoria, British Columbia and ride east through every Canadian province, and hundreds of cities and towns along the way. Our route is over 8,000 km, and we expect to average 150 km each day, 6 days a week for approximately 3 months. Our Spinning Wheels Tour team will include 2 riders with PD as well as 2 ride-along supporters to keep things moving. Along the way, we will be meeting with people whose lives are touched by PD, and encourage them to get moving with us, get engaged in support communities, and to set up their own group athletics.

We are not athletes, just people with the resolve to do what it takes to live well with this disease, and to encourage others.

Along the way, we hope to hear these words, "if they can do it, I owe it to myself to try".

We will also be seeking support from local charities in each Province that promote and facilitate people living with PD to embrace intensive athletics.

Please visit our website at www.SpinningWheelsTour.ca to make contact, offer your support, and play a role in improving the lives and futures of people living with PD.



Steven Iseman – co-founder of Rigid Riders & Spinning Wheels. Steve@spinningwheelstour.ca



Mike Loghrin- co-founder of Rigid Riders & Spinning Wheels. Mike@spinningwheelstour.ca



Jim Redmond – Spinning Wheels cyclist
Jim@spinningwheelstour.ca



Darlene Richards-Loghrin – Spinning Wheels cyclist and care partner
Darlene@spinningwheelstour.ca



Dancing with Parkinson's in-person classes

DANCING FOR ALL SENIORS WITH MOVEMENT DISORDERS

By Sarah Robichaud (founder of Dancing with Parkinson's) and Robert Davis (patient partner)

Dancing with Parkinson's (DWP) is a grassroots charitable program founded by professional dancer Sarah Robichaud in 2008 with the aim to bring seniors with Parkinson's disease (PD) out of isolation to connect and move with others in an artistic environment. Sarah's interest in Parkinson's began in 2007 when her client Andy Barrie (former CBC metro morning radio host) was seeking her help to manage the physical symptoms of his neurological movement disorder through exercise. Ms. Robichaud immediately enrolled in the Dance for PD teacher training program in NYC to learn how to help people living with Parkinson's through dance, and she made it her mission to provide weekly classes in Toronto.

Prior to the pandemic, DWP offered in-person dance classes to people with Parkinson's, their care partners and family members at 15 locations throughout the GTA.

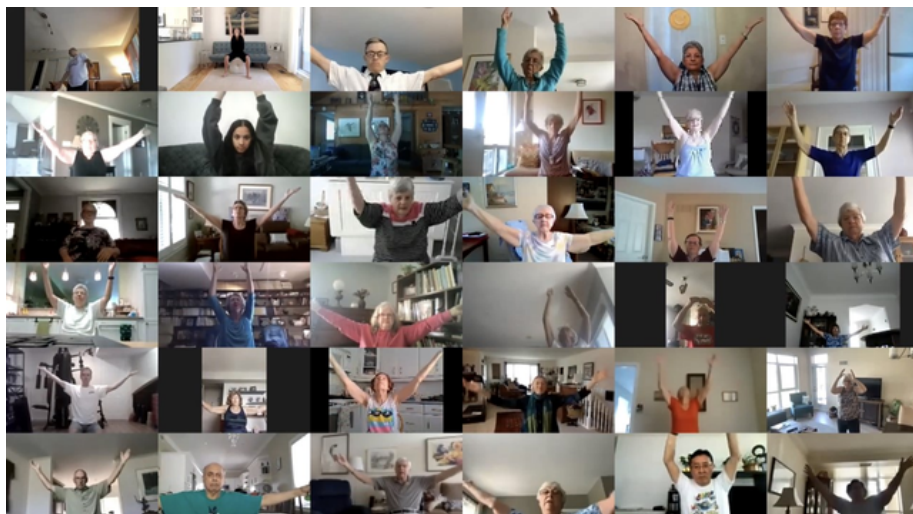
TESTIMONIALS

"JOINING DANCING WITH PARKINSON'S IS THE SINGLE BEST THING I'VE DONE FOR MYSELF SINCE MY DIAGNOSIS. IT IS SO GOOD FOR MY BODY, AND IT LIFTS MY SPIRITS."

"YOU HAVE NO IDEA WHAT YOU ARE DOING FOR PEOPLE WITH PARKINSON'S. YOU CHANGE LIVES ... YOU GIVE US ALL SOMETHING SPECIAL TO LOOK FORWARD TO EACH DAY. THANK YOU THANK YOU!!!"

"THANK YOU AGAIN FOR GIVING THIS GIFT TO US. IT IS JUST PHENOMENAL. IT GIVES ME SUCH POSITIVE FEELINGS ABOUT MY DISEASE."

"DANCING WITH PARKINSON'S HAS BEEN MY LIFE SAVER OVER THIS PAST YEAR."



Dancing with Parkinson's on zoom 7 days a week, for free

Like so many other organizations, the pandemic fundamentally transformed the way we deliver our programs. Overnight, we were forced to close all 15 in-person locations for people living with Parkinson's and began offering dance classes through an online platform for free every single day of the week to ALL seniors throughout Canada. Our evaluation of the program with the Evaluation Centre for Complex Health Interventions at the University of Toronto showed that the daily dance classes based on the DWP method are physically and emotionally beneficial for all seniors of different abilities and movement challenges who are participating.

Despite the isolation faced by many during COVID-19, DWP's community has become stronger and more connected than ever before. Seniors from across Canada, including those with various movement and cognitive challenges, tune in to see their dance family, make friends and share stories 7 days a week.

TO DATE

- Over 3,000 seniors across Canada have registered for our free classes and over 100 attend daily.
- Seniors with and without neurological conditions and movement disorders are tuning in from long-term care homes, seniors' residences and private homes every single day!
- Seniors dance with us in wheelchairs, walkers and even hospital beds. We make our classes accessible and welcoming to everyone of all abilities.

OUR IMPACT

Our online DWP classes were evaluated by the Evaluation Centre for Complex Health Interventions at the University of Toronto. We learned:

- Over 70% of individuals joined more than 4 classes per week
- 56% of respondents felt less isolated
- 49% felt less depressed
- 46% felt less anxious
- 85% of respondents had more energy



Our participants share what the program means to them in this touching video

DID YOU KNOW?

Did you know that over 100 seniors take our classes each day?! Dancers with and without Parkinson's disease are joining us from their homes, long term care settings, and rehab centres from across Canada. Since March 2020, we have been offering free classes 7 days a week...that is over 750 free classes in a row so far!





Awarded a community hero by the Toronto Raptors and MLSE

The Science Behind the Dance

We need to better understand how dance provides benefits to people living with Parkinson's. DWP is committed to ongoing research and evaluation to inform best practices and maximum benefit for our dancers living with movement disorders.

Our research team is led by board members Dr. Lorraine Kalia MD, PhD, FRCPC, Clinician-Scientist and Neurologist at the Movement Disorders Clinic at Toronto Western Hospital, and Dr. Jackie Bender, Scientist at the Cancer Rehabilitation and Survivorship Program in the Department of Supportive Care at Princess Margaret Cancer Centre.

Our research, evaluation and delivery partners include Ontario Brain Institute, Baycrest, Parkinson Canada, York University, Queen's University, University of Waterloo, University of Toronto, Evaluation Centre for Complex Health Interventions and Alzheimer Society of Toronto.

Recognition

In April 2021, The Raptors and MLSE awarded us a [community hero](#) award for our work during this pandemic to support isolated seniors.



Our work with seniors during the pandemic was also featured in a [segment](#) on Global News.



DWP was named by the Toronto Star as one of the [Top 10 best things that happened during 2020](#).



Come dance with us, everyone and every ability is welcome!

www.dancingwithparkinsons.com

At your Leisure

Articles we think you may find interesting, helpful or thought provoking. Enjoy!



Feeling Slumped? Stand Tall, Feel Great.

"Good posture breeds good breathing and this is essential for you to feel, think and function at your best."



Animals for Mind, Body, and Spirit Health.

"One of the easiest ways to enjoy watching wildlife is by having a bird feeder or birdbath."



Getting Started with Mindful Movement.

"Bring our awareness to our movement and focus on our breath or the way our body feels as it moves."

Brain Connections in Parkinson's Disease

By Tasnuva Hoque, MDC Clinical Research Coordinator

Imagine that you're driving down a road with no red lights or stop signs to slow you down. While that may seem like a very exciting idea, it is obviously very dangerous, since our roads are not all parallel, but interconnected in a number of different ways. For traffic to go smoothly in all directions, we have stop signs, red lights, and speed bumps to make sure no accidents occur. In much the same way, our brain also has regions that are interconnected where information in the brain flows via excitatory neurons (brain cells) that have properties depending on their location in the brain. For example, excitatory neurons in the primary motor cortex (M1) tell our hands or feet to move. Since excitation cannot go on forever, the same brain region also has inhibitory neurons that make sure the information slows down or stops whenever required. As someone with symptoms of Parkinson's disease (PD) will tell you, the ability to slow down or stop is as important as moving, if not more.

Transcranial magnetic brain stimulation (TMS) is a non-invasive technique to investigate these excitatory and inhibitory brain connections. Dr. Robert Chen (neurologist at the Movement Disorders Clinic) and his research team at Toronto Western Hospital have been utilizing TMS methods for the last 20 years with both healthy participants and patients with diagnosed movement disorders. TMS studies have indicated a reduction in the effectiveness of a connection called short-interval intracortical inhibition (SICI) in the

Transcranial magnetic brain stimulation (TMS) is a non-invasive technique to investigate excitatory and inhibitory brain connections.



Dr. Chen and James Saravanamuttu, author of the journal publication, demonstrating TMS in the Chen Lab

brain of someone affected by PD. Dr. Chen's team's investigational research continues to gain better understanding about when these changes start to happen in the brain.

Continued on next page...

In 2021, a research article published in *Clinical Neurophysiology* by James Saravanamuttu, a University of Toronto graduate student supervised by Dr. Chen, demonstrated how SICI circuits influence other connections within M1 in patients with PD. The protocol involved applying three TMS pulses on the M1 region of the brain and included 15 PD research participants with mild to moderate symptoms, along with 16 healthy participants who were of similar age as the PD patients. In healthy participants, it was found that SICI enhances circuits known as short-interval intracortical facilitation (SICF). However, in PD patients the influence of SICI on SICF was impaired. The investigators speculated that the impaired interactions between SICI and SICF in PD depends on shortcomings in inhibitory interneurons. Using the Unified Parkinson's Disease Rating Scale (UPDRS) to assess the severity of PD, the investigators also found that the abnormal influence of SICI on SICF was greater for patients who had more severe PD symptoms. This raises the intriguing possibility that SICI first becomes less effective in influencing other M1 connections before being dysfunctional, which is the time when the characteristic symptoms of PD become obvious.

Levodopa is a widely used medication to treat symptoms of PD. To verify if these interactions were sensitive to Levodopa, recordings were collected while patients were taking Levodopa, and then recordings were repeated after patients refrained from



The Chen Lab team at the 2019 Crania Conference in Toronto.

from taking Levodopa overnight for 12 hours. Investigators found that Levodopa treatment improved the impaired influence of SICI on SICF. This is the first study that shows Levodopa treatment is able to improve the impaired interaction between different M1 circuits.

Reference: Saravanamuttu J, Radhu N, Udupa K, Baarbé J, Gunraj C, Chen R. Impaired motor cortical facilitatory-inhibitory circuit interaction in Parkinson's disease. *Clin Neurophysiol.* 2021 Oct;132(10):2685-2692.

Link for full text of the publication:

<https://pubmed.ncbi.nlm.nih.gov/34284974>

Investigational clinical research studies such as these are integral to expanding our knowledge about movement disorders like Parkinson's disease.

We would not be able to do it without the generous time commitment and enthusiasm of our patient research participants at the Movement Disorders Clinic.

Research Participant Feedback

By Gordon Myers, Patient Advisory Board Chair and research participant

"Participating in research helps me connect with what is new and happening in the field."

** Anonymous*



"TMS was a novel experience and not unpleasant. When I'm in any research study, I feel that I am helping in facilitating a cure for Parkinson's."

** Anonymous*

Why participate in research?

For many this is a no-brainer (no pun intended), but some may need inspiration.

"After I was diagnosed with Parkinson's, I read the book 'Lucky Man' by Michael J Fox where Michael spoke about the different research studies he did. This spiked my own interest in participating in research and I've been doing it ever since."

** Anonymous*

Keeping a positive outlook is challenging as we hack our way through the movement disorder jungle, so for me, participating in research studies is an effective antidote and a way to get you moving and make you feel alive and inspired. Working with young (and not so young) neuroscientists along with the rest of the research team helps bring light to what can sometimes be a rather dark place.

"You need to build a level of trust with the research team. This trust comes about when the research team is sharing their knowledge with you whether it is the purpose, or the results, of their research." ** Anonymous*

It's highly unlikely that any single research study will dramatically affect your life or the life of anybody with a movement disorder. But that's not how it works. It's an accumulative process. Whether it's a seemingly benign observational research study compiling data from

thousands (maybe 100's of thousands) of participants, or it's a highly anticipated clinical trial for a promising new drug or procedure, the benefits are felt in the decades to come. From the data come predictions of trends that over decades expose weaknesses in the disease's armour and perhaps leads a new generation of researchers to a definitive biomarker. The drug trial might be a failure, but the drug itself may be repurposed and turn out to be an effective treatment for another disease altogether. The benefits don't always match the expectations, but one study at a time things do gradually change. The bottom line? No patient volunteers, no research. No research, no new and better treatments.

"Research can help us move forward. My medications help my Parkinson's symptoms now but many years ago these drugs would not have existed if there was no research. I'm thankful for that."

** Anonymous*

Please consider taking part in one or some of the research studies going on now and in the future at UHN. The work is endless and they need all types of volunteers, all of the time.

**Interested in learning more about research studies?
Send an email to mdcclinicaltrials@uhn.ca**

** Anonymous participant testimonials are compiled from an interview with a research coordinator at the Movement Disorders Clinic, Toronto Western Hospital.*

Research

Our research program is actively working to advance new therapies and biomarkers, to develop new ways to treat and deliver better care.



Advancing the understanding of movement disorders

More than 150 community members from across Canada participated in a nine part series of roundtable discussions, exploring the advocacy needs of Canadians living with Parkinson's. These roundtables and report are the first step in building the foundation of future advocacy efforts for Parkinson Canada. Read the full report [here](#).



Studies looking for participants!

We have several clinical trials and research studies that are actively looking for participants with a diagnosis of Parkinson's within the last 5 years. Contact us for details!

The PPMI study is looking to identify risk factors and markers of disease progression. Open to anyone with Parkinson's, not taking any medications for it, or anyone at risk of developing Parkinson's. Your symptoms will be tracked over time and periodic biosamples will be collected.

Parkinson's patients and family members needed for a study investigating differences in brain functions using TMS (transcranial magnetic stimulation) and LIFUS (low intensity focused ultrasound)

Looking for Writers and Musician's Dystonia patients for a study looking at brain connections using TMS and MRI (magnetic resonance imaging).

If you fit any of the criteria or are interested in other opportunities please contact mdcclinicaltrials@uhn.ca and a member of our research team will be in touch with you.

We have lots going on! Find a list of research studies [here](#).

Donations to UHN

Donating can be made by:

Phone: 416-603-5300

Donations are made by credit card. State you would like donations to be towards the Movement Disorders Research Fund, or another fund of your choice.

Online: One-time donations in support of the Movement Disorders Research Fund can be made through this form.
If you would like to donate to a different fund, use this form.

Monthly Giving: Donations can be made through this form. In the drop down where it asks "Direct my gift to" click on "Other" and in the text box you can state Movement Disorders Research Fund or another fund of your choice.

Gift and Estate Planning:

www.UHNfoundation.ca/ways-to-give/gift-in-your-will

The innovative clinics and programs being run through the MDC and IMDP (including this newsletter), are all paid for by philanthropy.



Toronto Western Hospital



Toronto Rehabilitation Institute

University Health Network encompasses the Toronto General and Toronto Western hospitals, the Princess Margaret Cancer Centre, Toronto Rehabilitation Institute, and The Michener Institute of Education at UHN. The scope of research and complexity of cases at UHN has made us a national and international source for discovery, education and patient care. We have the largest hospital-based research program in Canada, with major research in cardiology, transplantation, neurosciences, oncology, surgical innovation, infectious diseases, genomic medicine and rehabilitation medicine.

Thanks for reading!

We love to share your stories, tips, recommendations, anecdotes, testimonials, research experiences, photos and artwork! Let us know what you want to see more of. Feel free to email us at movementdisordersclinic@uhn.ca

Looking for more resources and information on movement disorders?

Take a look at our past editions:

[Winter 2022](#)

[Fall 2021](#)

[Summer 2021](#)

[Spring 2021](#)

[Winter 2021](#)

PDF's can be downloaded [here](#).

Sign up [here](#) to receive future issues directly in your inbox!

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