

the
Parkinson

press

Winter 2018 

DBS in Saskatchewan

An update from Dr. Mendez & his teams.

So Marijuana is Legal

... now what?

Easing the Pain of Parkinson's

Research into Cannabinoid Oils and Pain

Neurons that Fire Together,

Wire Together. Researching Neuroplasticity

 Parkinson Canada





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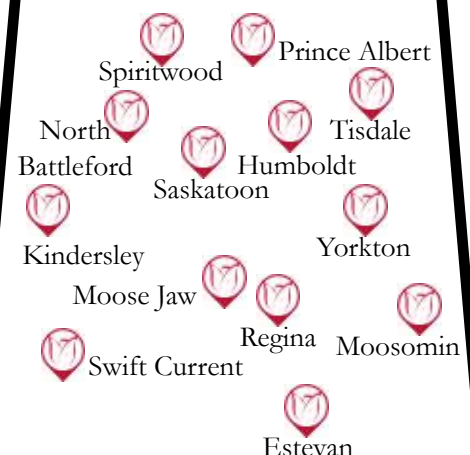
What We Do

Parkinson Canada is the national voice of Canadians living with Parkinson's disease. From diagnosis to discovery, we guide the way for Canadians to live well with Parkinson's disease through research, education, advocacy, and support. Whether you are an individual living with Parkinson's, a health care professional who treats them, or a family caregiver, we offer programs and services in communities coast to coast, in person, by telephone and online. The Parkinson Canada Research Program funds innovative research to search for better treatments and a cure. By working with all levels of governments, our advocacy initiatives focus on those issues of the greatest importance to the Parkinson's community.

Editorial Statement

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Find a Parkinson Canada Support Group near you!



ANOTHER YEAR IS COMING TO A CLOSE



Todd MacPherson, Managing Director

On November 3rd yet another sellout crowd poured into Saskatoon's Prairieland Park for the 10th annual Lows in Motion fundraiser. The event was exciting as always, but a little bittersweet as this was the final "Shaker." After 10 successful years and \$650,000 donated to Parkinson Canada, the committee made the difficult decision to end the event on a high note. I want to personally express my gratitude to the Low family, the committee and all those who made it such a premier event.

Change is a constant in life, as Heraclitus said, "There is nothing permanent except change."

I am very excited to announce that, we will be replacing this newsletter with a national Parkinson Canada newsletter. This is something we have been hoping to do for the past year or more. This new version of the newsletter will feature some great articles by experts from across the country. But don't worry, we will still have a section to highlight events, information and stories from Saskatchewan. Watch for the first edition of the Parkinson Post to be arriving in your mailbox or your inbox in the spring of 2019.

There are also changes happening in our understanding of Parkinson's disease. Slowly,

but surely, we are making advances through our research program. In this edition, we highlight two of the innovative, investigator-driven researchers funded by the Parkinson Canada Research Program. Since 1981, the Parkinson Canada Research Program has invested more than \$29 million in funding for:

- High-quality, innovative Canadian research by established and promising investigators.
- Discovery stage research where investigators test new theories and pursue promising new leads.
- Researchers at the beginning of their careers in order to foster the next generation of Parkinson's scientists.
- Novel research to build greater capacity, promote creativity and engage more researchers.
- More than 552 awards, fellowships, and grants that teach us more about diagnosing and treating Parkinson's disease.

As 2018 comes to a close, I look forward to 2019 with its changes and progress as we continue to create a better life for those living with Parkinson's today, and a world without Parkinson's tomorrow.

**There is Help and Hope at
Parkinson Canada**



Saskatchewan is fortunate to have two clinics providing Deep Brain Stimulation Services: the Royal University Hospital Neuromodulation Clinic, and the Regina General Hospital. Over the past five years, the clinics have steadily increased their ability to provide service for the people of Saskatchewan. A recent published survey indicated that people in Saskatchewan now have the best access nationally for this surgery: a truly remarkable accomplishment!

DBS is offered to patients with movement disorders such as Parkinson's disease and dystonia, as well as for essential tremors. Mental health applications such as depression and OCD are also being treated with this technology.

in Saskatoon and Dr. Buwembo in Regina), dedicated nursing teams, an electro-physiologist and computer engineers.



Dr. Vitali and the Saskatoon neuromodulation team

The surgeons are using the new scanners to determine exact placement for the electrode; there are currently three potential sites used within the brain, depending upon individual symptoms.



Dr. Mendez and the Saskatoon neuromodulation team

Under the leadership of Dr. Ivar Mendez, a solid Neuromodulation Program has been created, and state of the art equipment has been installed in the operating room in both sites. This team consists of the three neurosurgeons (Dr. Mendez and Dr Vitali



Dr. Buwembo and the Saskatoon neuromodulation team

A unique feature of the Program is its ability to offer distance services to patients, as part of the treatment process. The initial assessments are done at the clinics, including a psychological evaluation to ensure a good level of cognitive functioning. For some patients that live far away, however, the follow-up appointments can be carried out in a patient's home community at the local health centre or even at the patient's physician's office! The technology with the famous

"Doc in a Box" is becoming known nationally. This has been an enormous benefit for those who have had to travel such vast distances in the past.

The DBS program has become recognized across Canada for its excellence and innovation, and our community can be proud of what it has achieved.



Many within the Saskatchewan Parkinson's community have heard Dr. Mendez speak at Parkinson Canada Education conferences. There is therefore a keen interest in the Stem Cell Research program, and we are frequently asked to request updates on the progress of this program; Dr. Mendez recently provided us with that information.

As many of you know, this has been a collaboration between Dr. Mendez and his team with colleagues at Harvard and in Montreal. The actual manufacture of the cells will be occurring in Montreal.

This new generation of stem cell work involves taking cells from a person's own body; the bone marrow from the hip is being used. These cells are then transformed into neurons which produce dopamine. A robotic system has been enlisted to assist with the transformation of the cells. The process of ensuring standardized, clinical grade of stem cells has now been perfected; this phase has been a major step towards the actual clinical trials.

There has been tremendous progress to date, and the trials are perhaps 2 years ahead. Dr. Mendez is certainly aware of the great interest which our members have in this work. Many have asked how to be involved, what is the eligibility for clinical trials. He has committed to working with the community,

"when the time comes", in making the announcement of the commencement of these trials. An eligibility list with criteria and numbers of participants will all be established.

This is indeed ground breaking research, and we count ourselves fortunate that Dr. Mendez has chosen to work in our province. We appreciate that he has been so open and generous in sharing his work and progress with us since his arrival, and will closely follow the progress of this phase of the project.



The "Doc in a Box" Technology in Action



So Marijuana is legal... now what?

The issue of legal and medical cannabis (as marijuana is now usually called) can be confusing to sort out for many seniors and people with medical conditions: *would it be*

helpful; what should I be careful about; what do I need to know?

Sometimes it is difficult to know where to look for reliable sources. Up until recently, most health providers have been reluctant to give advice, due to this lack of solid research, and also due to the difficulty in the past of obtaining standardized doses. However, things are changing very quickly!

We know as well that Parkinson's is a very unique condition, and that people with PD may have differing responses to medicines. This is further complicated by the fact that they may also have a variety of other medical conditions.

Here is a basic introduction to the topic of cannabis use for Parkinson's. Readers are encouraged to consult with some of the many resources listed below, for more detailed information on this important topic.

1. How does Cannabis work?

- Humans have an internal endocannabinoid system, so receptors already exist which respond to the compounds called "cannabinoids" which are present in cannabis.
- Over 85 cannabinoids have been discovered within the cannabis plant, all of which are capable of interacting with this human endocannabinoid system. THC and CBD are the most researched of these, and the formulas or strains available are based on the percentage of them present
- In addition, more than 200 "terpenes" have been identified in cannabis. Terpenes are what make the characteristic smell of cannabis. They act in

a synergistic way together with cannabinoids, in a manner which is still being researched.¹

2. What are some of the most common uses which people with Parkinson's have tried?

- Symptomatic relief: some relief from symptoms such as pain, insomnia, dyskinesia, bradykinesia, anxiety and depression has been reported by some people. Again, a percentage of patients report relief with tremors has been reported, but the research is inconclusive at this time.
- Some preliminary research suggests that one of the components of cannabis, CBT, may have neuroprotective or immune-boosting properties. We are eagerly awaiting further research on this topic!

3. Cautions: are there any cautions I should be aware of?

As with any change in medications, use of any cannabis product should be discussed with a medical practitioner who is aware of each person's individual medical history.

Although cannabis has been considered generally "safe", there are certainly side effects which can occur. It is critical to learn about the different products which are available, i.e. what are the levels of THC and CBD in each? Consultation with a pharmacist knowledgeable on this topic is recommended. Fortunately, this service is increasingly available.

- **Cardiac:** For people with cardiac conditions, the potential for increased pulse or fluctuating blood pressure needs to be considered, as well as care in choice of product.
- **Psychological:** Dr. Monique Giroux, an American Neurologist, stated the following:
 - Psychoactive effects of marijuana can have negative short-term and long-term consequences. For example, sedation, apathy and depression

can worsen with use and exacerbate any sedating properties of anti-tremor medication.

- Marijuana can cause psychosis or altered mental states. The elderly, people with cognitive problems, dementia or mental illness may be more susceptible to experiencing these side effects. The combined risk of marijuana in these populations is unknown.
- Apathy can lead to lifestyle changes or habits such as lower activity and exercise levels, poorer eating habits and social withdrawal, which can impact the brain and general health.
- Stress certainly worsens tremor and marijuana may indeed have a positive impact on stress physiology. Since there are risks to using marijuana, other alternatives that combat stress such as meditation, guided imagery, exercise and yoga should be considered as treatments with lower risk and perhaps broader general health gains. These anti-stress techniques should not be overlooked as part of a holistic approach to managing tremor.²

Those with anxiety and or depression may find that the literature states both relief as well as caution in using cannabis, which can be confusing! That's why it is so important to discuss with a health provider and pharmacist, as well as exercising caution in choosing which product to use, as the THC/CBD levels are critical factors.

And, of course, impaired judgment and motor coordination can double the risk of a motor vehicle accident and this increases substantially if combined with alcohol²

- **Drug Interactions:** Cannabis may interact with several drugs. Make sure to tell your health care practitioner which prescription and non-prescription drugs or herbal products you are currently taking, particularly:
 - Any drugs which slow down the central nervous system, causing drowsiness. These may include sleeping pills, tranquilizers, some pain

medications, some allergy or cold medications, or anti-seizure medications.

- Other drugs may include antiretroviral drugs used in the treatment of HIV/AIDS, certain anti-depressants, stomach acid inhibitors, certain antibiotic and antifungal medications, certain heart medications, and Saint John's Wort.³

A Note About Doses and Product Selection: As per the pharmacists at medSask, no one yet knows the optimal THC/CBD ratio for PD, or the best dosing. Finding your optimal dose / product will require some experimentation – they suggest to start with low doses and increase slowly.

Also, one should note that although edible cannabis is not legal at this time, if this type of use is chosen, it is important to understand that slower digestion in PD will result in delayed absorption and onset of effect. It can take as long as 3 hours (perhaps longer in PD) for the effects of edibles to begin, so be careful not to increase the dose in this time frame.

RESOURCES



There is a wide range of information on the following sites which will help inform on issues concerning cannabis use. The Community Development Coordinators in Regina and Saskatoon can

assist those who do not have access to the Internet. Members of the community are encouraged to use the telephone service provided by medSask described below.

- Use the websites and webinars of Parkinson Canada, and other credible Parkinson's organizations, including the World Parkinson Congress. Parkinson Canada has issued a policy statement on cannabis use, with background information and supporting documentation. Parkinson Canada is currently sponsoring a Neurologist, Dr. Susan Fox, with a research grant looking at pain and PD.

Continued on page 11

PARKINSON CANADA SUPERWALK™

Just like that, another successful SuperWalk is in the books, and we are so proud of Saskatchewan for joining hands and demonstrating the power a community can have when it comes together for a good cause. Everyday heroes, extraordinary hope!

Saskatchewan SuperWalk's grew once again this year, bringing the amount of Walks to a total of six: Swift Current, Estevan, Moose Jaw, Saskatoon, Ituna, and Regina. Altogether, these six communities were able to raise \$141,000 towards research, advocacy, and support for people living with Parkinson's.

The first Walk of the year took place in Swift Current on September 1st and raised over \$19,000. Always a fun time, this year's event also included a raffle table featuring a beautiful quilt generously made and donated by Carol Kuntz of the Swift Current Parkinson's Support Group.

The walk in Estevan was unique in that they chose to take on a "Support Group SuperWalk" this year. This is a new type of Walk that we've been encouraging as a great way to start a SuperWalk in your community because it starts small, involves your existing support group, and needs minimal planning. The Walk took place on September 6th in place of their regular Support Group meeting, and despite its small size, was able to raise \$4,150.

Soon after Estevan was the Moose Jaw SuperWalk on September 8th. A unique story came from the MooseJaw walk when Kurt Luchia, son of Sandra Luchia who coordinates the Moose Jaw Walk, made a 400km trek across Saskatchewan in a 1956 Willy's Jeep. He and his late father, Perry Luchia who lived with Parkinson's, restored

the Willy's Jeep to its former glory. Kurt raised \$3,550, adding to the \$18,000 that was raised at the Walk.

Saskatoon's SuperWalk took place on September 9th in Meewasin Park north. Larry Fowke led the procession, being recognized by the Saskatoon Support Group as their local hero. Altogether, Saskatoon raised \$62,500.

Our last two Walks, Regina and Ituna, took place on September 15th. The Regina Walk had an exciting addition when WestJet generously provided tickets for two return flights anywhere WestJet travels! This raffle item proved very popular at the walks across the province. In the end, Mike Gamble from Regina was the lucky winner. The proceeds of the raffle made a sizeable contribution into Regina's total amount raised of \$31,700.

This was Ituna's first year hosting a Walk, coordinated by Jennifer Poissant of Hubbard, SK, who wanted to do something to help after her husband was recently diagnosed with Parkinson's. Ituna's community spirit did not dissappoint, and they managed to raise \$5011. An amazing job by a small community!

Thank you to every walker, donor, and volunteer for helping us exceed our provincial goal and raise more dollars than ever before!





Kurt Luchia's Jeep Cruise for Parkinson's
(pitstop in Chamberlain)



Estevan SuperWalk



First Ituna SuperWalk



Warm up before the Swift Current walk gets started



Edwards School of Business volunteering in Saskatoon



Saskatoon Walk Hero, Larry Fowke

There is
HOPE
in my
WALK



Regina SuperWalk



Saskatoon SuperWalk



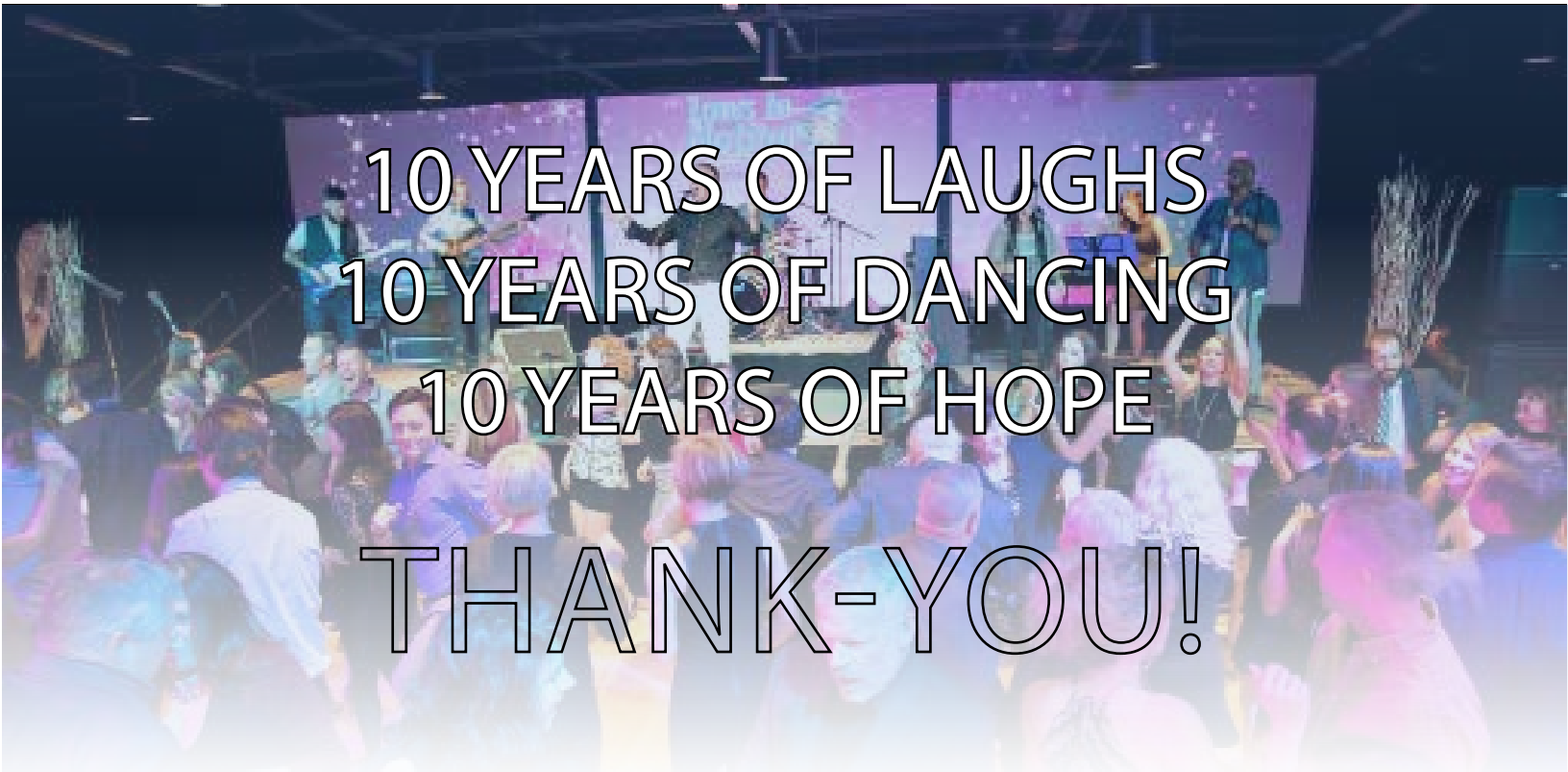
A family "mini-SuperWalk" in Naicam



Moose Jaw SuperWalk



The annual Regina SuperWalk group photo.



10 YEARS OF LAUGHS 10 YEARS OF DANCING 10 YEARS OF HOPE THANK-YOU!

On Saturday, November 3rd, the Lows in Motion organizing committee welcomed yet another sellout crowd to Saskatoon's Prairieland Park to celebrate its 10th and final anniversary. Over the past decade, this unique and energetic "Shaker" has earned the reputation of a premier Saskatchewan event and Canada's most attended Parkinson's fundraiser.

Lows in Motion's mission has always been twofold: raise funds to support Parkinson Canada - Saskatchewan, and shed light on what it means to live with Parkinson's disease. Year after year, the committee has delivered on this goal by putting together an exceptional evening of music, comedy, and community.

We at Parkinson Canada - Saskatchewan are honoured to be the chosen donor recipient for this event. Since 2009, Lows in Motion has raised an impressive \$650,000 in net proceeds for our organization. This money has helped us facilitate six province-wide education conferences, add several staff members who provide support and education throughout the province, expand our Saskatchewan support groups to 13, make significant contributions to the Parkinson Canada Research Program, and the list goes on.

To the organizing committee members, sponsors, volunteers, and nearly 9,000 individuals who have attended Lows in Motion over the years: thank you. Your generosity and support has given tremendous hope to the Parkinson's community.



 LowsInMotion.com

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(continued from page 7)

- **Health Canada** has a comprehensive overview of cannabis issues on their website

Saskatchewan Resources:

- **medSask** This is a service available by phone as well as through the Internet. It is managed by licenced pharmacists at the University of Saskatchewan. They are familiar with the issues which have been raised about the pros and cons of cannabis use with Parkinson's, and they have access to all of the most recent research available. Their response can be tailored to your unique situation, e.g. current prescriptions, over the counter meds, herbs, and other medical conditions: they are a wonderful resource to answer your questions & concerns. They are available during the day and evenings, and provide a service which truly invaluable!

Phone: 1-800-667-3425 or 306-966-6340 (8 am - midnight M-F, 5 pm - midnight Wknds & Holidays)

- **1:1 Counselling:** There is an increasing interest with pharmacists to provide personal, evidence- based counselling and consultation concerning cannabis use. Their stated goal is to help you understand how medical cannabis may affect your current medication and health conditions by:

- Reviewing your medications
- Discussing potential risks and side effects
- Providing education on medical cannabis

There may be a charge to you for this service; ask when you contact them.

Other valuable websites:

- **CAMH:** The Centre for Addiction and Mental Health has a vast catalogue of verified, research-informed mental illness material. Their website has a comprehensive overview of the benefits and risks known thus far on cannabis use. There are useful brochures available called: 10 Ways to Reduce Risks to Your Health When Using Cannabis, for the public and for health professionals.
- **Guidelines for Seniors:** The Coalition for Seniors' Mental Health is a national coalition of professionals and concerned organizations which have joined to promote research and resource sharing on issues of importance for seniors in mental health. In December, 2018, they are scheduled to release medical guidelines for health professionals to highlight health issues which seniors face with cannabis use.

¹ Dr. Sanjay Gupta, A New Outlook, Internet Article

² Dr. M. Giroux, Marijuana and Tremor, International Essential Tremor Foundation

³ Health Canada website, Medical Cannabis



Stay up to date on upcoming events, the latest Parkinson Canada news, and helpful tips and tricks for managing your Parkinson's!

<https://www.facebook.com/parkinsonsaskatchewan/>





Dr. Susan Fox
Associate Director, Movement Disorders Clinic
Toronto Western Hospital
\$45,000 over 1 year

Pain is a constant companion for as many as 10 percent of people with Parkinson's disease. Unfortunately, most of them can't tolerate the sleepiness and confusion regular pain medications induce.

That's why Dr. Susan Fox, a Toronto neurologist and professor at the University of Toronto, is investigating a different source of pain relief. Fox is conducting a pilot study, along with her colleague Dr. Tiago Mestre in Ottawa, to see whether 15 people with Parkinson's disease will benefit from oils made from cannabinoids—the active compounds in marijuana.

Currently, people with Parkinson's may experience pain in their muscles and joints because of the stiffness and rigidity the illness causes. Some also report a sharp pain, often in their legs or feet, that is more puzzling because doctors can't determine its exact cause.

"Some people call it central pain," says Fox. "It's probably mediated by some brain mechanism reflective of Parkinson's. People express this as an unpleasant burning, stabbing pain, and it's very difficult to treat."

Fox, who treats people with Parkinson's at Toronto Western Hospital's Movement Disorders Clinic,

hopes her study will discover whether people with Parkinson's can tolerate oils, and experience less pain after using them. She also wants to identify the best strength and dosage for people to use.

Almost every day, one of her patients asks her about trying marijuana to relieve their tremors or rigidity.

But although marijuana might help people relax and feel less rigid temporarily, there's no evidence that it relieves those symptoms long-term, she says.

"There's always this misconception that cannabis can help anything and everything," she adds.

Fox would rather see her patients try approved and safe medications to relieve tremors and rigidity, so that's why this study is focused on determining if there is any benefit of cannabis oils to treat pain.

Fox's study will also assess whether these oils cause drowsiness and lower blood pressure—already a concern for people with Parkinson's. There is also a small risk the oil could induce or worsen hallucinations—a symptom some people are already experiencing.

If Fox's research demonstrates that people can tolerate cannabis oil and it doesn't have worrisome side effects, then her results could lead to a larger, randomized controlled trial.

"There are clear risks and side effects with cannabis, so you weigh up the risk versus the benefit ratio," she says.

Most importantly, Fox hopes the cannabis oil will not only help people with Parkinson's feel better, it will also relieve a burden for their caregivers.

"It's an unmet need," she says. "It's very challenging for the family, as well, to watch their loved one in pain and agony."



Cricia Rinchon
Krembil Research Institute,
University Health Network
\$30,000 grant over 2 years

As an undergraduate studying neuroscience at Western University, nearly every course Cricia Rinchon took mentioned Parkinson's disease at one time or another. She knew it was the second most commonly diagnosed neurological problem, but she also learned just how much we still need to understand about this disease. This lingering sense of mystery prompted her to pursue Parkinson's as the focus of her graduate school career, which has taken her on a fast-track to doctoral studies at the University of Toronto.

At 22, Rinchon is working with some of the most prominent investigators in the field, at the University Health Network's Krembil Research Institute. Her work builds on the established success of deep brain stimulation (DBS), a technique that treats the symptoms of Parkinson's with the use of an electrical pulse generator that surgeons implant to deliver stimulation to deep brain structures. Rinchon combines this approach with a complementary method called transcranial magnetic stimulation (TMS), which applies electrical pulses from outside a patient's brain. By matching these two sets of signals, she's exploring the possibility that together, they might restore balance in the network of brain cells that Parkinson's damages.

"We are manipulating the way neurons talk to

each other," she explains. "You will often hear this phrase: neurons that fire together, wire together."

That phrase refers to plasticity, the term for the brain's remarkable ability to reorganize its structure in response to damage. Just as physiotherapists work with stroke patients to "rewire" pathways in the brain that have been affected by the stroke, Rinchon hopes combining DBS and TMS can help repair the ravages of Parkinson's.

"We're investigating to demonstrate that this technique shows promise for a clinical trial," she says.

This preliminary research involves recruiting people with Parkinson's, who have provided Rinchon with personal insight into this ailment. They enhance her research journey.

"We like to treat them as honoured guests," she says. "These are people who undergo so many frustrating challenges from day to day. But they always seem to have such high spirits and optimism when it comes to participating in research—I find this incredibly refreshing."

Working directly with people living with the disease, instead of solely in a lab environment, keeps Rinchon inspired.

"Here, I am reminded every day I collect data about why doing this research is important."

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In Memoriam

We offer our sympathy to the families, friends and communities who have lost loved ones over the past months, and we extend our sincerest thanks to those who have donated in their memory.

Marion Andrews
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Stephania Buryniuk
Edward Camber
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Joy Clayton
Marvin Cook
Alexis Cooray
Peg Don
Ned Dudley
Dennis Ehman
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Sherry Vranai
Madeline Weisbeck
Jean Williams
Jim Zehr

*Those we love don't go away,
They walk beside us every day.
Unseen, unheard,
but always near.
Still loved, still missed,
and very dear.*





Parkinson Canada

Knowledge Network

The Parkinson Canada Knowledge Network is a collection of webinar and podcast resources that will enhance your understanding of Parkinson's disease. You can find all of the 2018 episodes on Parkinson Canada's Soundcloud and Youtube channels.

2018 Webinars

Feb 13, 2018	How to Keep Intimacy Alive in Parkinson's Disease
Mar 16, 2018	Discussion about Parkinson's Disease: An Introductory Guide
May 8, 2018	Falls Prevention 365 Days a Year
Jun 12, 2018	Advanced Parkinson's Therapies: DBS and Duodopa
Aug 14, 2018	Alternative Parkinson's Therapies: Music & Dance
Nov 13, 2018	PSP and Multiple System Atrophy (MSA) - Signs, Symptoms and Treatment
Dec 11, 2018	Incontinence and Voiding Dysfunction in Parkinson's

2018 Podcasts

January 2018	Early Stage Parkinson's: The Newly Diagnosed
April 2018	Mid-Stage Parkinson's
July 2018	Late-Stage Parkinson's
October 2018	Caregiving through the Stages of Parkinson's

To access all these resources go to: www.parkinson.ca/resources/knowledge-network/

The 2019 schedule will be posted soon.

Return undeliverable items to:

