

MDC CONNECTIONS

WINTER 2022

Year in Review

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Photographer
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Welcome to the *fifth* edition of *MDC Connections* — a publication series of resources to inspire you to do more, to move more, and to learn more. Empowering you with information and offering ways to connect.

We invite you to contribute to this publication and provide feedback. Tell us what you like! We're listening.

Email us at
movementdisorders@uhn.ca

Editorial Notes

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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.

MDC Connections 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



Welcome back readers!

Happy New Year!

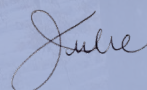
Without a doubt, this past year has been memorable and full of emotional highs and lows. I couldn't be more thankful to have you in our audience and community.

A year ago, we rolled out our first issue of *Connections*. The idea was sparked by the loneliness we all felt during this pandemic. Our daily routines were disrupted, and we found ourselves sitting with, well, ourselves! Unable to see loved ones, classes cancelled, support groups gone virtual, and we knew that many of our patients were struggling. We wanted to empower you with reliable information and ways to generate community. *Connections* quickly grew into a forum to share tips on mental health, exercise, alternative therapies, and your stories. We wanted you to know that you're not alone. One year later, we still do.

As part of our ongoing mission to co-design all we do with our patient partners, we engaged our Patient Advisory Board (PAB) to help. We strategized and shaped each issue together, showcasing your stories and advice. These feisty PAB members rose to the task and we learned so much from each other building every issue together.

This past year was filled with new and exciting programs, events and media appearances. Starting on page 4 you'll find highlights of the amazing work the teams at the Movement Disorders Clinic (MDC) and the Integrated Movement Disorders Program (IMDP) accomplished, in the face of all the challenges and strain that has been placed on all of us.

As I reflect on what transpired over the last year, I can only express sincere optimism for what lies ahead. Let's all face 2022 with gentleness and self-compassion. Recognize how difficult this year has been and that we are getting through it together, a little more each day. Take a slow and relaxed breath. Lower your shoulders and enjoy life's wonderment. If you like nature, spend a moment inhabiting the natural world with Missy Mandel's stunning images, starting on page 17. Enjoy!



Julie Racioppa, Editor

Making patients
partners

Year in Review



New frontiers in
neurodegenerative disease
research

2021 was a big year for the Movement Disorders Clinic (MDC) and the Integrated Movement Disorders Program (IMDP)!

Highlights include:

The Toronto Western Hospital Patient Advisory Board (PAB) works in close partnership with faculty and clinicians at the MDC and the IMDP. Read more by clicking on Dr. Sarah Lidstone's photo (top left).

Our Faculty made waves in the Krembil Brain Institute's magazine this year (top right).

Dr. Naomi Visanji (middle right) studies the biology of the brain and gives a message of hope.

You may recognize Yu-Yan Poon, RN (bottom right), honored as a Healthcare Hero. Well deserved!

Dr. Lorraine Kalia (middle left) shares promising research advances. Together, the Kalia's (below left) made waves with multiple media appearances and webinars. A power team to watch in 2022 and beyond!

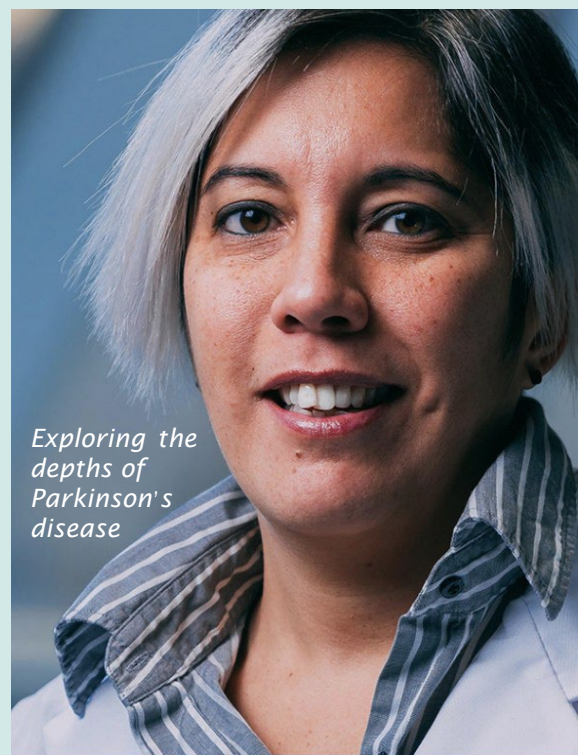
**Click any of the photos to read more!*



Focused ultrasound and stem
cell therapy



4



Exploring the
depths of
Parkinson's
disease

Know Your Heroes

Year in Review

ROUNDTABLE KICK OFF!

Exploring the realities of a Parkinson's diagnosis, and the barriers and challenges of accessibility to care.



Highlights continued...

Parkinson Canada kicked off a series of Roundtables with experts from across the country, including Dr. Sarah Lidstone. The Roundtables identified a crucial need to increase government support for access to a better care system and earlier diagnosis.

In August 2021 Dr. Alfonso Fasano interviewed with CTV News addressing the impact of social media related to the pandemic and vaccines on Functional Neurological Disorder (middle top left).

Dr. Lorraine Kalia appeared on an episode of the Fifth Estate about a mystery brain disease in New Brunswick (middle top right).

Get caught up with our 2021 Speaker Series events (right and left) and check out the DBS discussions (below).

What is functional neurological disorder and is it connected to COVID19 vaccines?

Functional Neurological Disorder



UHN Movement Disorders Speakers Series *Virtual Event*

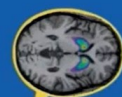
The Patient Advisory Board (PAB) at
Toronto Western Hospital Movement Disorders Clinic:
Making Patients Partners



A mystery brain disease affects residents in New Brunswick.

UHN Movement Disorders Speakers Series *Virtual Event*

Cannabis – How it may help with the severity of PD symptoms



Stimulating Discussions on Deep Brain Stimulation (DBS)

"Our DBS webinars ran without a hitch and were very well received. The events were organized and run by the PAB and were truly patient driven both in content and style."

A big thank you to the DBS clinical team for their generosity and willingness to tackle the difficult questions. Thanks also to the patients and care partners who shared their stories so eloquently".

Gordon Myers, PAB member and event chair

C Stimulating Conversation on DBS - ... Watch later Share 1/2



Stimulating Brain Discussions on DBS
November 3 and December 8 | Zoom Webinar

Watch on YouTube

Year in Review

SPRING ISSUE 2021

We loved creating our quarterly newsmagazine for you in 2021, covering physical and mental wellness. Here's a look back on our issues.

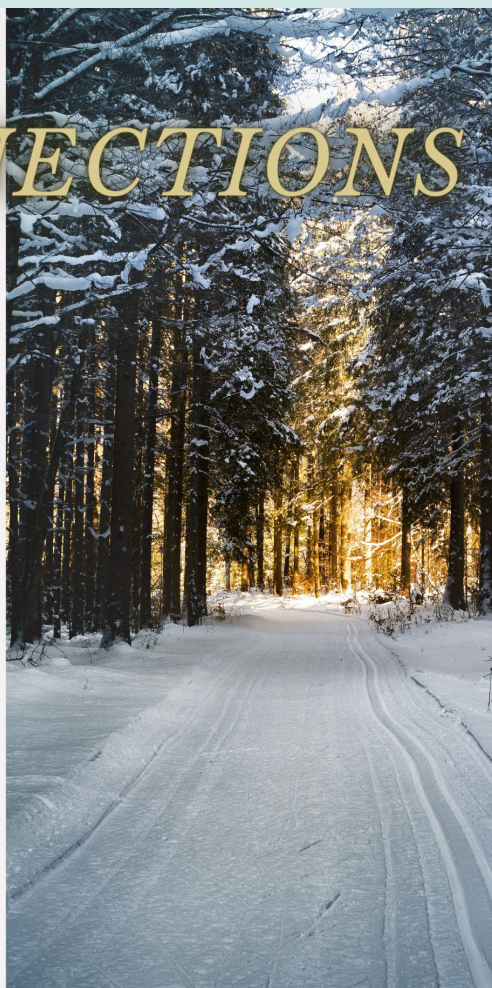
MDC CONNECTIONS

WINTER ISSUE 2021

Helping you maintain momentum with powerful resources is our priority.

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MDC CONNECTIONS

April is Parkinson's Awareness month!

Learn about Parkinson Canada's "No Matter What" campaign *p.8*

Helping you maintain momentum with powerful resources is our priority.

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Hear from our experts! Register for the 2nd virtual **UHN Speaker Series** *p.4*

Read our COVID-19 vaccine statement *p.5*

Mental wellness check-in

Apathy explored with Dr. Zurowski *p.15*

Mental wellness resources *p.18*

Virtual support communities *p.21*

Self care reminders *p.24*

Mindfulness *p.26*

SUMMER ISSUE 2021

MDC CONNECTIONS

For all the caregivers and care partners!

One Care Partner's 22 Year Journey *p. 8*

The Contribution of a Loyal Friend *p.11*

A Communication Circle Maintains Social Interaction *p.16*

10 Years In - What I Wish I'd Known *p.19*

Wellness check-ins:

Recommendations for Every Care Partner *p.10*

Caring for the Carers *p.12*

Helping you maintain momentum with powerful resources is our priority.

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MDC CONNECTIONS

FALL ISSUE 2021

Functional Neurological Disorders

Masterclass with an invisible illness *p.7*

Don't you want to know? *p.14*

Mind-body connection: hear from our experts! *p.10, 11 & 12*

Music therapy *p.22*

Stimulating Brain Discussions - upcoming DBS events! *p.32*

COVID-19 and telemedicine *p.33*

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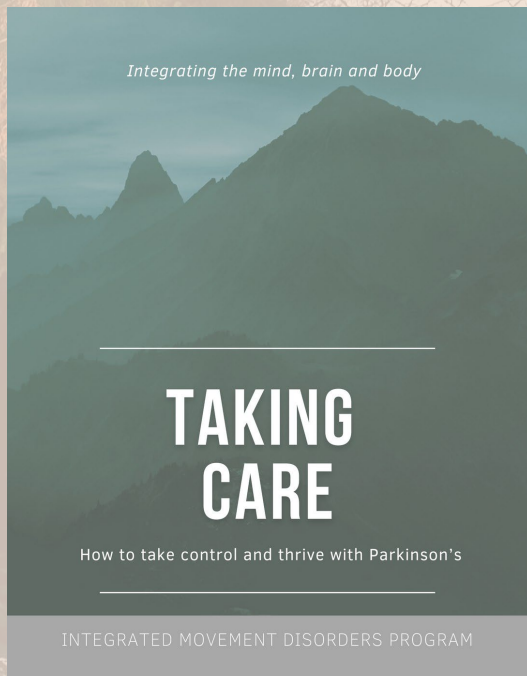
Ask our Neuro PT

By Haseel Bhatt, PT

In March 2021 we piloted an 8-week Parkinson's rehabilitation program called Taking Care.

Taking Care is a skill-based program that emphasizes self-management through education and skills building. Participants learned how to recognize when they are running low, strategies to build that reserve back up, and ultimately how to best take care.

After receiving some great feedback from our PAB and program participants, our next steps are to launch a new and improved version of Taking Care and study the benefits of this program in greater detail.



Program workbook with activities to connect, recharge, adapt, and move more!

"Parkinson's impacts every part of person's life, and there are many ways that people can learn to thrive that go beyond medication and doctors appointments. Our patients ask us over and over again, "what can I DO NOW?" We have created this course to answer that very question."

- Excerpt from Module 1, Taking Care



Haseel Bhatt, Neurological Physiotherapist

“

I liked the interaction and the information regarding exercise and the brain. The activity with the highlights was eye opening!



86% 'agreed' or 'strongly agreed' that the program fulfilled their expectations'

79% 'agreed' or 'strongly agreed' that their understanding of the psychological effects of Parkinson's improved

93% 'agreed' or 'strongly agreed' that they can better deal with problems related to Parkinson's

100% felt they would participate again

100% would recommend this program to other people living with Parkinson's

Ask our Mental Health Nurse

By Keschey Marcelle, RN

During 2021, we piloted two new nurse-led clinics at the Integrated Movement Disorders Program (IMDP) for patients with movement disorders. These clinics helped patients develop strategies, build skills, and supported their rehabilitation towards self-management. Both clinics are run by Keschey Marcelle, our IMDP mental health nurse.

Our **Rapid Access Mental Health clinic** provides mental health evaluation for our patients with Parkinson's disease (PD) and non-pharmacological (non-medication) treatment strategies.

Many patients with movement disorders, like PD, struggle with mental health issues such as anxiety, depression, grief, and coping challenges.

Evaluating and managing some of these issues are within the scope of a mental health nurse. The benefits of this new model of care are much shorter wait times, empowering patients and families with skills and knowledge to care for their mental health, and partnerships with psychiatry and community mental health programs. We learned that we need a social worker to expand our ability to link patients to local resources. Due to the overwhelming success of the clinic, we will keep it going and study the impact on patients and families and the economic benefits of the model.

The **Drop-in clinic** is the next step in the rehabilitation journey for individuals who have completed our therapy programs, both in mental and physical health. The goal of any rehab program is for individuals to learn skills that they can apply in their daily life to accomplish their goals. This year, we started a Drop-in clinic to support individuals to continue building their independence and achieving their goals. Offered one day a week, patients call to book their own appointments and determine the agenda to focus on what is most helpful to them.

Interventions commonly provided included encouragement and reassurance, with resources to continue working towards functional goals.

Sometimes there is a review of learnt skills and brainstorming new management strategies, or it's a time to celebrate successes and talk about challenges. Patients find support simply knowing this service exists. The clinic was only used by half of the patients it was offered to! This tells us it is another model of care that can reduce wait times and be economically beneficial.



Keschey Marcelle, mental health Nurse

Highlights from the Rapid Access Mental Health clinic

- 100 appointments in 1 year
- Less than one month wait time for an appointment
- Anxiety, uncertainty, and mood changes were the top concerns
- Care partner burnout was very common
- Only 3% required a referral to psychiatry
- High rates of patient satisfaction

Patient Advisory Board (PAB)



A letter from the outgoing chair, Hugh Johnston

The PAB Committees achieved their multi year objectives in 2021. Providing a critical eye on program development, education, the research experience, and more.

The *Communication & Education Committee* worked brilliantly together. With weekly meetings they were very active and exceeded everyone's expectations. The *Clinical Ad hoc Committee* directly engaged with the clinic patients and provided solid advice to faculty and staff on how to improve the patient experience. The *Research Committee* gained a skilled patient leader, Dr. Soania Mathur, engaged in incorporating the patient voice into the whole research enterprise, recruiting staff, and communicating results directly to all the patients who volunteer their time participating in studies. Several projects are already lined up for 2022.

Founding any board where patients, family members, faculty and staff volunteer their time and actually "get results" isn't achieved by "ticking all the boxes".

It takes people with complimentary professional skills who work well together in accordance with shared values. It takes people with an attitude and intensity to get results focused on what the MDC needs. It takes people who can create synergy with, and act on advice from people with diverse backgrounds.

Finally, the right to pass the baton to the next Chair is when, as founding Chair, you have someone like Gord Myers to pass it on to.

It has been an honour and a pleasure to work with the TWH MDC patients, family members, faculty and staff who both enjoy, and are effective at this type of collaborative work. As Chair, I will have done my job if as a group they found our two years together a rewarding experience; and as a bonus I will have been given the gift of meaningful work, leveraging the experience and mentoring I've had good fortune to receive over my own career.

Hugh Johnston
Outgoing Chair, Patient Advisory Board
Toronto Western Hospital
Movement Disorders Clinic



Hugh Johnston, avid sailor

Patient Advisory Board (PAB)



A letter from the incoming chair, Gordon Myers

It's impossible to have lived the last two years and not think about the turmoil and upset caused by the COVID-19 pandemic. That said, I feel incredibly fortunate to be able to say that my experience over that time has been incredibly positive and surprisingly productive as a direct result of my experience with the MDC PAB. The people I've met and worked on committees with since the Fall of 2019, from faculty and staff to patients and care partners, have given my inner activist a focus that I didn't know it needed and I am grateful to all of them for that. Perhaps none more than now former member Linda Redford who has resigned from her board position but not before leaving an indelible mark on the PAB and its members. The committees we served on together were effective and productive in a large part due to her hard work and determination. We thank you for that Linda and wish you well going forward.

The last two years, which for me will always be known as the first two years of the MDC PAB, will also be forever highlighted by Hugh Johnston's inspired leadership as chair. Hugh has a skill set that both commands the room and offers up genuine empathy to the people around him. I am humbled that he has put my name forward to be board chair and hope that I can keep the PAB moving forward on the course he has so deftly set. This incoming chair will be leaning on Hugh for the next few months so as a colleague and friend I thank him for setting the standard so high.

I am excited about the future of the PAB and looking forward to seeing the board's role grow and evolve in lockstep with the MDC. Every two months we meet, Neurologists, therapists, staff, patients and care partners alike to discuss the issues that matter to us. I believe we have a unique opportunity, as an advisory board for a world class centre of excellence, to make a real difference in the lives of the patients and care partners who attend the TWH MDC for the treatment of their particular movement disorder.

Gordon Myers
Incoming Chair, Patient Advisory Board
Toronto Western Hospital
Movement Disorders Clinic



Gord and his wife Alix at a Blue Jays game

Hear it from Harry

By Harry Forestell, PAB member

Give yourself a break... accommodating Parkinson's Disease (PD) at home and at work.

Of all the challenges I anticipated after being diagnosed with Parkinson's, the least of my worries was shirt cuffs. It turns out to be one of the most aggravating aspects of daily life with a movement disorder.

As a news anchor my day is filled with a myriad of challenges... research calls, deadlines, hurried interviews, editing tape, writing scripts and, yes, buttoning shirt cuffs. I'm a shirtsleeves kind of guy who likes to roll them up and get to work. When it comes time to go on air, the sleeves come down, cuffs get buttoned and the jacket goes on. This can happen several times a day as we record pre-taped segments for the show. What was once an unconscious act that required no more thought than breathing, is now an exercise in physical agility that can touch off an explosion of expletives, sighs and foot-stomping frustration.

The struggle to execute this smallest of acts with any kind of digital dexterity results in a twisting, twirling dance macabre. As my unruly fingers struggle to guide button and buttonhole to a satisfactory union, underlying dyskinesia turns the effort into a full body exercise. Disconcerting in the middle of a newsroom when you're trying to downplay the daily manifestations of a chronic movement disorder.

Therein lies the problem. The effort to appear "normal" among colleagues in the workplace can be a challenging, emotionally draining and ultimately futile effort. You can't hide the inevitable effects of PD. As much as it is considered an "invisible disability" with characteristics that may be unique to each individual, sooner or later it will become apparent that Parkinson's is a factor that can't (and shouldn't) be ignored.

While I haven't made a point of broadcasting my condition to the workplace, neither have I kept it a secret. Those in my own program team know, because I think it unfair not to be completely up front with them, especially on days when PD is getting the best of me. I have also disclosed my condition to select senior managers, so that on those occasions where I may need time off for clinical assessments or treatments, or additional time or supports for specific work assignments, nobody will be surprised.



Harry Forestell, on set at CBC news

To date, there has been no reluctance on the part of my employer to work with me to anticipate future needs and challenges that may crop up in this journey with PD. It's clear everybody is waiting for me to make the first move. I know too that there are considerable workplace protections for employees with chronic conditions. The difficulty comes in setting personal goals that will reasonably anticipate the effects PD will have on diminishing my ability to continue to work with the pace and energy I had pre-PD.

Inevitably the biggest barrier to accessing accommodations in the workplace for coping with PD may be my own stubbornness. An unwillingness to admit that the inexorable changes that come with a chronic movement disorder like Parkinson's will require significant modifications to how I live and work. Modifications that at this still-combative stage of PD may smell more to me like capitulation than accommodation. Like those cuffs I wrestle with. What if I just gave myself a break and didn't roll them up multiple times a day. Maybe it's time to move to short sleeves. After all, who's going to accommodate me if I don't accommodate myself?

Harry F.

--
Harry Forestell
 Host
 CBC Television
 CBC News, New Brunswick at 6
 Fredericton, NB.

Movement Disorders and the Workplace

Deciding when to inform your employer and coworkers about your condition is a decision only you can make.

The first thing you should do is check with Human Resources about the policies at your workplace.

If your symptoms are affecting your performance, disclosing sooner may be advantageous. It opens the dialogue, can ease anxiety and help dispel common misconceptions about movement disorders.

Sharing your diagnosis may lift a burden and bring relief. You may find you have more support than you expected. It will also raise new questions for you and your coworkers, it may change your work relationships. Recognize other peoples behaviour may shift due to their own experiences and personality, most likely this has nothing to do with you.

Things to consider

Before you tell your supervisor about your diagnosis, think about how they will take the news. The first thing they may wonder (whether you like it or not) is, "How is this going to affect company workflow and productivity?"

Research your company's benefits or perks, such as flexible work hours or working from home. Consider getting a workplace ergonomic assessment. Consider shifting out of a physically demanding role.

An Occupational Therapist (OT) can help identify tools and tricks to adapt your work environment to suit your needs.

Inform your employer with a fact sheet about your disorder. The Movement Disorder Society has downloadable leaflets on many movement disorders.

The Michael J. Fox Foundation guides Part 1 and Part 2 can help you decide when to start the conversation and how to manage it.

Talk to your health care provider if you have concerns.

Reassure your employer you are confident you can still do your job well, and that together you can find solutions that will benefit you both. **Many people with movement disorders continue to work for a long time in their careers.**

If possible, provide an example of someone with a movement disorder that is able to perform their job successfully, bring them into the conversation if feasible.

Disability Tax Credit T2201

By Linda Redford, PAB member

At some point a movement disorder can impact daily living. People may need to hire a therapist (physical or emotional support) or buy mobility devices. This article reviews the Canadian Revenue Agency (CRA)

Disability Tax Credit – Form T2201 and how it is relevant to people with movement disorders.

The CRA website describes the disability tax credit (DTC) as a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay. The **purpose** of the DTC is to provide for greater tax equity by allowing some relief for disability costs, since these are unavoidable additional expenses that other taxpayers don't have to face.

Being eligible for the DTC can open the door to other federal, provincial, or territorial programs such as the registered disability savings plan, the Canada workers benefit, and the child disability benefit.

There are two aspects of the T2201 process:

1. The medical process for identifying eligibility
2. The annual income tax process for claiming the credit

The Medical Process for Completing the T2201 Form

You can access the Disability Tax form T2201 at the **Canada Revenue Agency site**. This site includes **Step-by-step instructions** for filling out Form T2201.

Note: if you Google T2201 it will bring up a lot of private companies that will, for a fee, help you prepare the form but most people I know did it themselves with no problems.

You can download the T2201 form and print it. A medical professional needs to sign the form. Some family doctors will ask the family to fill out the details and the doctor will review, update and sign the form. Some doctors prefer to fill out the details themselves.

Beware of section A – many people read the criteria in section A and none of that is relevant. It is section B that applies to people with a movement disorder. This is where you describe the **impact** of the disorder on daily living.

- Pages 2 & 3 ask if a condition is markedly restricted, for example:
 - o Balance – the person has falls.
 - o Speaking - the person with some conditions can't be heard by others because the muscles are tight and both enunciation and volume are restricted.
 - o Limited mobility – the person walks slowly and is generally restricted.
- Pages 4 & 5 ask about cumulative effect of significant restrictions.
 - o On the bottom of page 4 it asks for the date the cumulative effect of the impairment began. Taxes can be re-done for prior years if the application is accepted.
 - o On page 5 it asks you to describe the effects of the impairment on daily living.

Note: you are asked to input a date when this impact on daily living began. If your application is approved by the government in 2021 but the disorder impact began in 2018, previous years' tax returns will be recalculated and you will get a refund for those years.

The Annual Income Tax Process for Claiming the Credit

The website describes After you send Form T2201 – Step by step process. Every year the tax credit will reduce the amount of tax to be paid. I don't know these details as I have a tax accountant that prepares the income tax statements for me and my husband. There are a number of benefits we are entitled to and she keeps up to date so that our tax forms are as efficient as possible to benefit us.

Giving back

By Melinda Davis, PAB member

Many of our readers like to make donations around this time of year. You will find here information on how to donate in support of our Movement Disorders Research Fund, or another UHN fund of your choice.

Donating to the UHN Foundation 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

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.

In 2019, Toronto General Hospital was named among the world's **Top 10 Hospitals** by *Newsweek* magazine. We were ranked first on **Canada's Top 40 Research Hospitals** list for 2018, and have been consistently ranked at the top since the rankings began by Research Infosource Inc. in 2011.



From exceptional patient care to amazing innovations in health care carried out at our hospitals, your gift will help us pursue the knowledge that will make all our lives better.



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



Our PAB like to give back. Here are some additional charities the PAB like to donate to

Melinda Davis

Established in the 1980's the Movement Disorders Clinic (MDC) has grown to be the largest of its kind within Canada and a world leader in Parkinson's care and research. Melinda hopes that the clinic will add Ataxia to that list.

Melinda's own personal donations page supports the MDC.

<http://support.tgwhf.ca/goto/melindadavis>

Gordon Myers

The Centre for Addiction and Mental Health (CAMH) is Canada's largest mental health teaching hospital and one of the world's leading research centres in it's field. The organization conducts ground-breaking research, provides expert training to health care professionals and scientists, develops innovative health promotion and prevention strategies, and advocates on public policy issues at all levels of government.

<https://www.camh.ca/>

Peter Gilli

What started as a grassroots effort has now become a global mission by those committed to the health and well-being of individuals inflicted with Functional Neurological Disorder (FND). A donation to FND Hope will help raise FND awareness, provide patient support and advance research.

<https://fndhope.org/>

Linda Redford

People living with Parkinson's are at the centre of everything they do at Parkinson Canada. They provide education and services to support you, your family and your health team, online, by telephone and in person.

<https://www.parkinson.ca/>

Hugh Johnston

Since 2009, Porridge for Parkinson's has been serving up an elegant morning fundraiser, featuring a brunch prepared and served by top Toronto chefs!

<https://porridgeforparkinsonsto.org/>

Benjamin Stecher

Benjamin Stecher is a consultant and patient advocate (not only for the MDC!) but also for the Cincinnati Cohort Biomarker Program. It is a five-year study on neurodegenerative diseases.

To learn more about the study:

<https://ccbpstudy.com/>

To donate to the study:

<https://foundation.uc.edu/donate>

Harry Forestell

What started 75 years ago as Foster Parents Plan, helping children displaced by war around the world, is now Plan International Canada. Plan Canada continues to advocate for children's rights with gender equality as a foundational objective. Seeking to tackle the root causes of gender inequality and remove barriers that keep children, especially girls from reaching their full potential.

<https://plancanada.ca/>

Dr. Soania Mathur

Dr. Soania Mathur is not only on our patient advisory board but also for the Michael J. Fox Foundation for Parkinson's Research. The foundation is dedicated to finding a cure for Parkinson's disease through research and ensuring development of improved therapies for those living with the disease.

<https://www.michaeljfox.org/>

Arts & Artists

Missy Mandel is a wildlife photographer from Toronto. Deeply connected to nature, Missy follows her passion, letting it fuel her mental and physical health in a way that speaks her truth.

Connected with Nature

By Missy Mandel

At the age of 53, I learned that I had early onset Parkinson's Disease. The diagnosis shook me to my core. A fear of the unknown gripped my soul and body, and I sensed a very real threat to the life I had planned for – a life of peace and tranquility.

As a wildlife photographer, I agonized most over how my diagnosis might ultimately impact my ability to hold to a camera – which, over the past two decades, has become somewhat of an appendage to my body. How would I come to grips with the symptoms and challenges that lay ahead? There were countless questions that had no answers, and I was riddled with worry.

My greatest fear was losing my ability to be a photographer – and, therefore, my ability to be me. Over time, though, I came to realize something critical: That which frightens me is also that which pushes me to dispel my fear. Indeed, perhaps paradoxically, the thing that I am most afraid of losing has emerged as the thing that has kept me going.

Since my diagnosis, photography has been my lifeline. My passion for photography has only deepened, becoming the driving force behind my progress, both mentally and physically. I vowed not to let my disease define me. Rather, I am using it as fuel to further me.

In my eyes, nothing is more therapeutic than connecting with nature, camera in hand. Wildlife has always resonated with me profoundly. When I am surrounded by the beauty of the wild and the life that inhabits it, I am instantly at peace. A calmness overcomes me when I lock eyes with my subjects and capture their emotions with the click of my camera. The animals have no fear of me, nor do I of them. We belong to each other in that moment.



Missy in the wild, in her element.

Photography pushes me to get outside each day, to move around and use my body, and to keep my mind sharp. It challenges me to perform at my best, to highlight the beauty of my subjects, and to use my artistic inclinations to present the magnificence of nature to those who see my work. It gives me great pleasure to have my images adorn a wall or mantle, where others can, for a fleeting moment, inhabit the beautiful world of the wild.

Rather than letting fear consume me, I have instead opted to channel my anxiety into action. For me, that means continuing to pursue my passion, regardless of how my disease might one day hinder my abilities to do so. At present, I am still able to grip my camera tightly and capture the splendor that surrounds me. That, in and of itself, is a gift that I will never take for granted.

I cannot control what fate has dealt me, but I can control how I live my life – and whether I choose to live it to the fullest. The moment I accepted this reality was the moment I began my journey to a stronger, more accepting, and more peaceful me.

www.missymandel.ca

Instagram [@missymandel_photography](https://www.instagram.com/missymandel_photography)



Common loon and chick



Snowy owl in flight



Grizzly landscape



Grizzly plunge



Fox and tree



Fox kit and mom - admiration

You can find more of Missy's
photography at:

www.missy_mandel.ca

Instagram
[_@missymandel_photography](https://www.instagram.com/missymandel_photography)





Move that BODY!

The following activity guide is designed to inspire you to move more and get out of your comfort zone. Some of the links are specific to particular movement disorders, like PSP, or Parkinson's. We suggest trying anything that's within your activity level and seems reasonable for you to do!

Thanks Chris M. for recommending the [Balance, Strength & Vocal Projection](#) class!

Start
slow

Listen to
your body

	(lower intensity)	(medium intensity)	(higher intensity)
Aerobic 	<u>FUN SEATED WORKOUT</u>	<u>LOW IMPACT AEROBICS</u>	<u>10-MINUTE DANCE WORKOUT</u>
Strength Training 	<u>3 SEATED LEG EXERCISES</u>	<u>10-DAY CHALLENGE</u>	<u>ROCK STEADY BOXING</u>
Balance Training 	<u>BALANCE EXERCISES FOR SENIORS</u>	<u>BALANCE STRENGTH & VOCAL PROJECTION</u>	<u>1 HOUR CHAIR YOGA</u>
Flexibility 	<u>SEATED BACK PAIN RELIEF STRETCHES</u>	<u>GENTLE STRETCHING FOR SENIORS</u>	<u>STRETCHING AND EXERCISES FOR CAREGIVERS</u>

Alternative Therapies

PROGRESSIVE RESISTANCE TRAINING

In this article, Gord Myers explains the challenges in finding an exercise regimen that worked for him and the benefits of what he landed on: progressive resistance training.

By Gordon Myers, PAB member

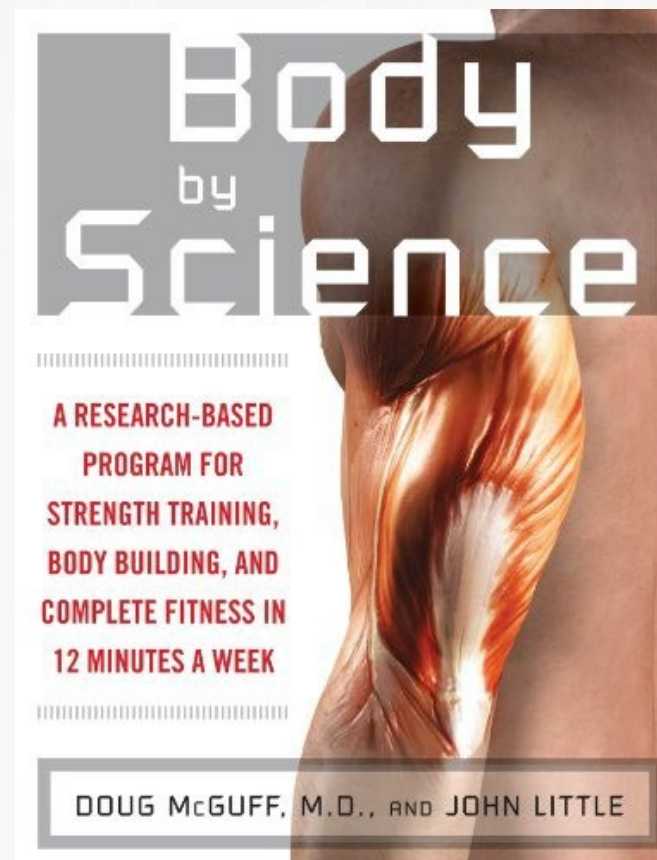
I was diagnosed with Parkinson's Disease on April 1st, 2010. My first reaction was disbelief and shock which, over time, evolved into relief and resolve. Relief that whatever was causing the tremor in my right hand, my lack of facial expression, tendency to move slowly and my chronic depression, had a name. And resolve to do whatever I could to help myself, beginning with regular, focused exercise.

At that time exercise wasn't as widely recommended as an effective treatment for Parkinson's as it is today, but thankfully, I stumbled on a misplaced pamphlet at my first neurologist's office advertising One Step Ahead, a physiotherapy clinic that focuses on patients with neurological diseases, especially Parkinson's. They were great and got me headed in the right direction, but with a disappearing, self-employed income and no health plan I had to find an affordable and effective alternative before my critical illness insurance was depleted.

I started working with a personal trainer in my neighbourhood doing circuit training. I'd see him a couple of times per week and work out on my own the other days. In about 6 to 9 months I lost 30 pounds and attained a level of fitness higher than I'd ever reached. Exercise is not a cure, but, done regularly, it does lessen and even slow down just about every motor and non motor symptom Parkinson's has to offer. The key is compliance. You need to choose regular exercise (s) that you will willingly do for the rest of your life. I was grateful to Jamie, my affordable personal trainer, but I didn't see daily, circuit training sessions as being sustainable going forward.

Enter my friend and health guru Tony and his discovery of a particular brand of progressive resistance training he'd read about in a book called Body By Science. He highly recommended I check it out and pointed me towards Medxpf, a gym in Toronto that specializes in this very specific protocol. Trainer and owner Blair Wilson got me started and I haven't looked back. It goes like this:

"In about 6 to 9 months I lost 30 pounds and attained a level of fitness higher than I'd ever reached."



PROGRESSIVE RESISTANCE TRAINING

THE METHOD

rep: one lift and return

set: the number of reps you do without setting the weight down

1. It can be done using **free weights** but, especially for beginners, and since eliminating risk of injury is of primary importance, the exercises are done using Medx machines which are state of the art **resistance training machines** that use the same principles as the iconic Nautilus system.

2. All movement is done **as slowly as possible**, again, to virtually eliminate the risk of injury as well as to eliminate any momentum and to keep your muscles "under load" throughout each rep.

3. Each exercise is done with **80% of the maximum weight you can lift and lower** while keeping good form.

4. The goal is to reach a minimum of **90 seconds, and no more than 2 minutes, under load**, before reaching muscle failure (fatigue that prevents you from keeping the weight elevated). Over 2 minutes you increase the weight, under 90 seconds you decrease it.

5. The primary routine (this evolves over time) is 5 big muscle exercises with a minimum 30 seconds rest after each set. **"The big five" are: Chest press, shoulder press, row, pull down and leg press.** Each movement is done to muscle failure. The last 15 seconds of every set is brutal. The number of reps is of little importance. It's that time under load that counts the most.

6. The whole routine takes **less than 20 minutes** and is most effective done **once per week** to allow for a full recovery as your body adapts to the stress of the workout.

7. The routine, to be most effective, should be done with a **personal trainer** both to optimize health benefits and eliminate risk of injury



Efficiency is key, Medxpf uses a timed approach of slow and continuous weight lifting.

PRT at Medxpf uses a time-efficient method, building strength through weight lifting.

PROGRESSIVE RESISTANCE TRAINING

THE SCIENCE

In my opinion, the science is pretty clear of the effectiveness of progressive resistance training (PRT) on Parkinson's motor symptoms, especially bradykinesia and strength loss leading to balance problems, a loss of confidence, and a generally less active lifestyle. There have been many studies done that point to PRT as a vital part of your exercise routine, Parkinson's or no Parkinson's. Just like the drugs we dutifully take to treat our symptoms, exercise should be considered a prescription you follow as an essential part of your treatment. At this time I cannot quote a study or peer reviewed paper that specifically points to the Body By Science protocol as the most effective choice. What I can do though is share what it has done for me and how it has been an incredibly valuable component of my fitness regime. It has allowed me to carry on with an active lifestyle including pick up hockey in the winter and golf in the summer (I still walk and carry 18 holes whenever possible) and long walks with my dog Duke. I've been going to Medxpf 3 to 4 times per month for almost 10 years. I guess you'd say I'm fully compliant.

"it has been an incredibly valuable component of my fitness regime. It has allowed me to carry on with an active lifestyle including pick up hockey in the winter and golf in the summer, and long walks with my dog Duke."

In the "Body by Science" book the authors dispel a lot of the myths around weight/resistance training and point to the broad range of health benefits, from stimulating mitochondrial activity to improving cardiovascular health. Your risk of falling is greatly reduced and if you do fall your risk of injury is lessened. For people with Parkinson's disease some type of strength training is essential and there is no more effective and safe a system for improving muscle strength than that laid out, in great detail, in "Body by Science."

For more information see:

"Body by Science"

by Dr. Doug McGuff M.D. and John Little

Medx gym in Toronto:

Blair Wilson

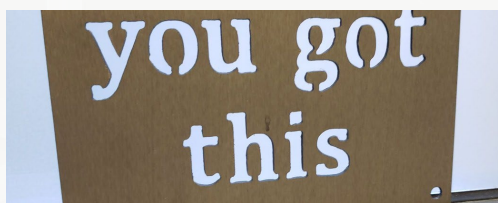
<https://medxpf.com>

(416) 360-1450

Related studies:

1) [Effects of aging and Parkinson's disease on motor unit remodeling: influence of resistance exercise training](#)

2) [Evidence-Based Resistance Training Recommendations](#)



The leg press is a powerful movement and often shows dramatic improvement. It also is likely a beneficial contributor to an active lifestyle, especially for people with balance and endurance concerns.

The Medxpf gym, leg press at Medxpf, and a motivational mantra to keep you going!

App Alert!

Apps are a great way to try out something new and connect with others. In every issue we provide suggestions for apps that we think provide value. Try one out! Or try them all!

How did you
sleep last
night?



Sleep Monitor: Sleep Recorder & Sleep Cycle Tracker

Sleep Monitor helps you build better sleep habits. Start and end your day with gentle soothing music. Record your sleep noises and get a detailed analysis of your sleep cycles.

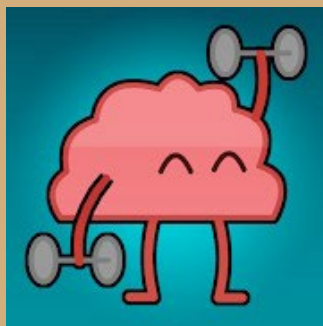
How you
feel
matters!



Happify

Start by choosing a happiness track - "Conquer your Negative Thoughts", "Cope Better with Stress" or "Grow Your Inner Strengths" - then complete weekly activities to help change your outlook.

Aerobics for
your
neurons!



Neurobics

Keep your brain in shape with fun mind games. Train your brain in short sessions - a couple of minutes each day. Stimulate areas of your brain: Memory, Concentration, Problem-Solving and Calculation.

Keep track
of your
symptoms



ADPA - American Parkinson Disease Association Symptom Tracker.

Keep track of your symptoms, create a report to share with your care team, track your medications and get helpful notifications and reminders.

Tech Help

This section highlights technology tips, tricks, software and programs aimed to empower you to try new things and be comfortable with technology.

Suggestions are welcome - feel free to email us at movementdisorders@uhn.ca

In the Fall '21 issue we told you about SteadyMouse, assistive software to keep your cursor steady if your hand is shaking.

Well, there's also a foot pedal that can eliminate the need for mouse clicks altogether! The Savant Elite2 (SE2) ergonomic foot pedal requires intention and a firm press, so would not be good for leg tremor or contractions of the leg or feet.



Finding it hard to hit the right little keys on your phone? Me too. Especially with cold hands! Instead, try tapping the little microphone 🗣️ or saying "Hey Google" (or "Hey Siri" if you're an iPhone user) and asking a question or telling your phone to do something, like setting a timer. Even if you have some difficulty in the delivery, or phrase it poorly, assistive technology is pretty good at correcting.

Do you use Google Docs? There's a really handy voice typing feature there! Go to Tools, scroll down to that little 🗣️ Voice Typing. Give it a shot!

UHN MDC does not endorse any of the products mentioned.



Have a virtual visit coming up?

UHN has important tips for preparing for a virtual visit [here](#) and [here](#).

The **Movement Disorders Clinic** has a quick guide [here](#) and more details [here](#).



Wellness

With everything going on in the world, there is so much information that is difficult to process. Take a breath, lower your shoulders, and take a moment to pause.

Be happy in the moment,
that's enough.
Each moment is all we need,
not more.
— Mother Teresa

Epson Salt Foot Bath

The next time you've had a busy day on your feet, try this simple, back-to-basics ritual to relax. Even if your feet aren't particularly sore, it's a great and inexpensive way to take extra care of yourself. Or treat a special someone and run them a warm foot bath. Epson salts, warm water, a clean bucket and a towel is all you need! Cue the relaxing music...



Four Ways to Calm Your Mind in Stressful Times

Most of us are really good at activating our adrenal system and getting wound up and stressed out. But how do you wind down? Research suggests there are practices that not only feel good but also put us into a relaxed state—a state from which we can cope better with whatever life throws at us.



Four Ingredients for Human Well-Being

Our everyday social structures have changed, some have even (temporarily) disappeared. Psychologist Dr. Elizabeth Markle explains how some people react to a sudden loss of normal, and how to intentionally incorporate movement, nourishment, connection and taking care of your inner well-being to help you live well throughout turbulent times. Back to the basics!



At your leisure

A few hand picked articles we think you may find interesting, helpful or thought provoking. Enjoy!

Double click
an image to
take you to
the article



Feeling Slumped? Stand Tall, Feel Great

Almost two years of global stress will probably have impacted your posture. Good posture sets the foundation for good breathing, which helps you to think, feel and function at your best.

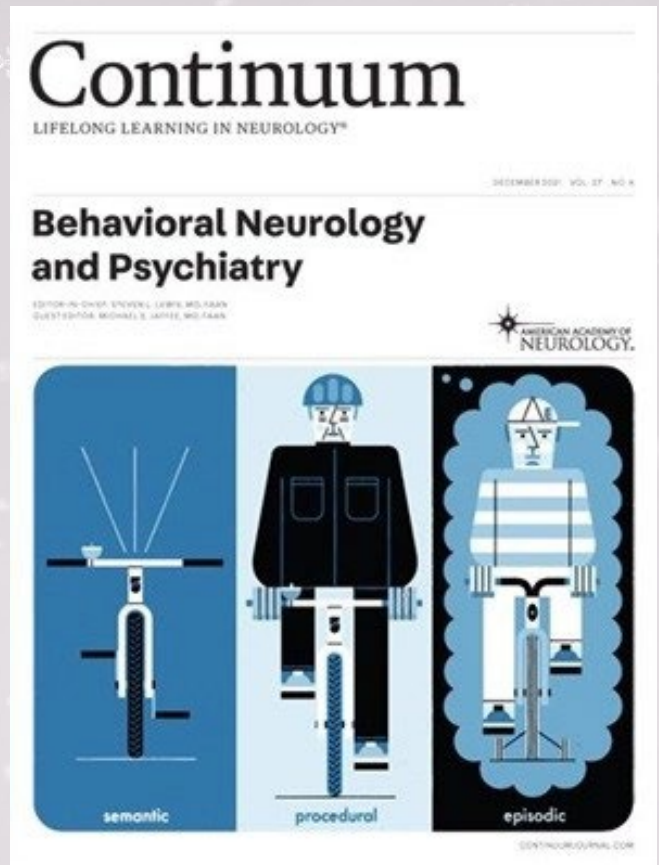
"Standing up tall and stretching our arms overhead has an uplifting effect on our minds"



Functional neurological disorder: lighting the way to a new paradigm for medicine

In a thought provoking essay published in the academic journal Brain, Mark J. Edwards gives reason for using Functional Neurological Disorder to inform how all neurological disorders should be treated.

"Recognize and invest in the science and expertise that will truly allow us, as scientists and clinicians, to become partners with the patient. Partners in understanding, moulding and finally recreating in a better form what it is, personally, to be ill."



Twilight and Me: A Soliloquy

Published in Continuum, the author, Dr. Daniel Alejandro Drubach, a behavioural neurologist has been diagnosed with Dementia with Lewy bodies (DLB). With a unique perspective of patient and physician, he talks about coping, about fear, and the importance of hope.

"Her beautiful smile has been stored in my book of precious memories, a catalog, or diary, where I write down precious events, people, and all other instances of beauty so that they can be recalled when no longer remembered."

MDC Research Program

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

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. It's open to anyone with *Parkinson's* who are not taking any medications for it, or are at risk of developing Parkinson's. Your symptoms will be tracked over time and periodic biosamples will be collected. Let us know if you're interested!

HANDDS-ONT is a cutting edge, technology-driven study, using a remote sensor. Facilitated in the participant's home and community, this study provides personalized health & activity reports. Join us if you are diagnosed with *Parkinson's* and currently taking medication for it.

**See next page for the study advertisement.*

If you have *Parkinson's*, are experiencing *bothersome pain*, and are interested in hearing more about the Cannabis study we'd love to hear from you! You must not be currently using Cannabis.

Parkinson's patients and *family members* needed for a study investigating differences in brain functions using TMS (transcranial magnetic stimulation).

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

Get in
touch with
us!

If you fit any of the criteria or are interested in hearing about 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](#).

Clinical Trials Ontario (CTO)

provides support and information about clinical trials.

CLINICAL
TRIALS
ONTARIO

Learn about clinical trials, what they are, your role, your rights, and what questions to ask the clinical team. Find a clinical trial in their Clinical Trials Finder.

CLINICAL
TRIALS
FINDER

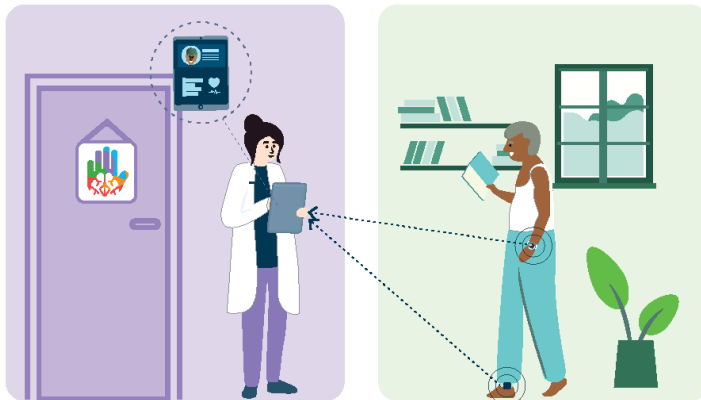
POWERED BY
CLINICAL TRIALS ONTARIO

Get involved with the ONDRI - Ontario Neurodegenerative Disease Research Initiative!



Volunteer with us to better understand your health and help advance brain research

We are utilizing the latest remote sensor, genetic and molecular technologies — paving the future of dementia care and research — **right in your home and community.**



Health in Aging, Neurodegenerative Diseases and Dementias in Ontario (**HANDDS-ONT**) is a technology-driven research study focused on you.

Eligible Study Participants*

- People diagnosed with:
 - Alzheimer's Disease
 - Mild Cognitive Impairment
 - Amyotrophic Lateral Sclerosis
 - Parkinson's Disease
 - Frontotemporal Dementia
- People who are post-Stroke
- Adults living independently with no diagnosis of a neurodegenerative disease/stroke.

* Must be an Ontario resident to participate.

Study Features

Receive these benefits



Personalized health & activity reports



Advancing science & community health

Your data is collected virtually in your home and community for 7-10 days



Wearable health & activity sensors



Health questionnaires

Visit a local lab



Blood sample

Contact study organizers

☎ 437-882-8335

@ www.ondri.ca/handds

🌐 handds@ondri.ca

Study is Research Ethics Board approved.

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. Email us at movementdisordersclinic@uhn.ca

Please fill out a short SURVEY so we can get to know you a bit better!

Looking for more resources and information on movement disorders?

Check our past editions of MDC Connections.

Fall 2021

Summer 2021

Spring 2021

Winter 2021

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

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

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