

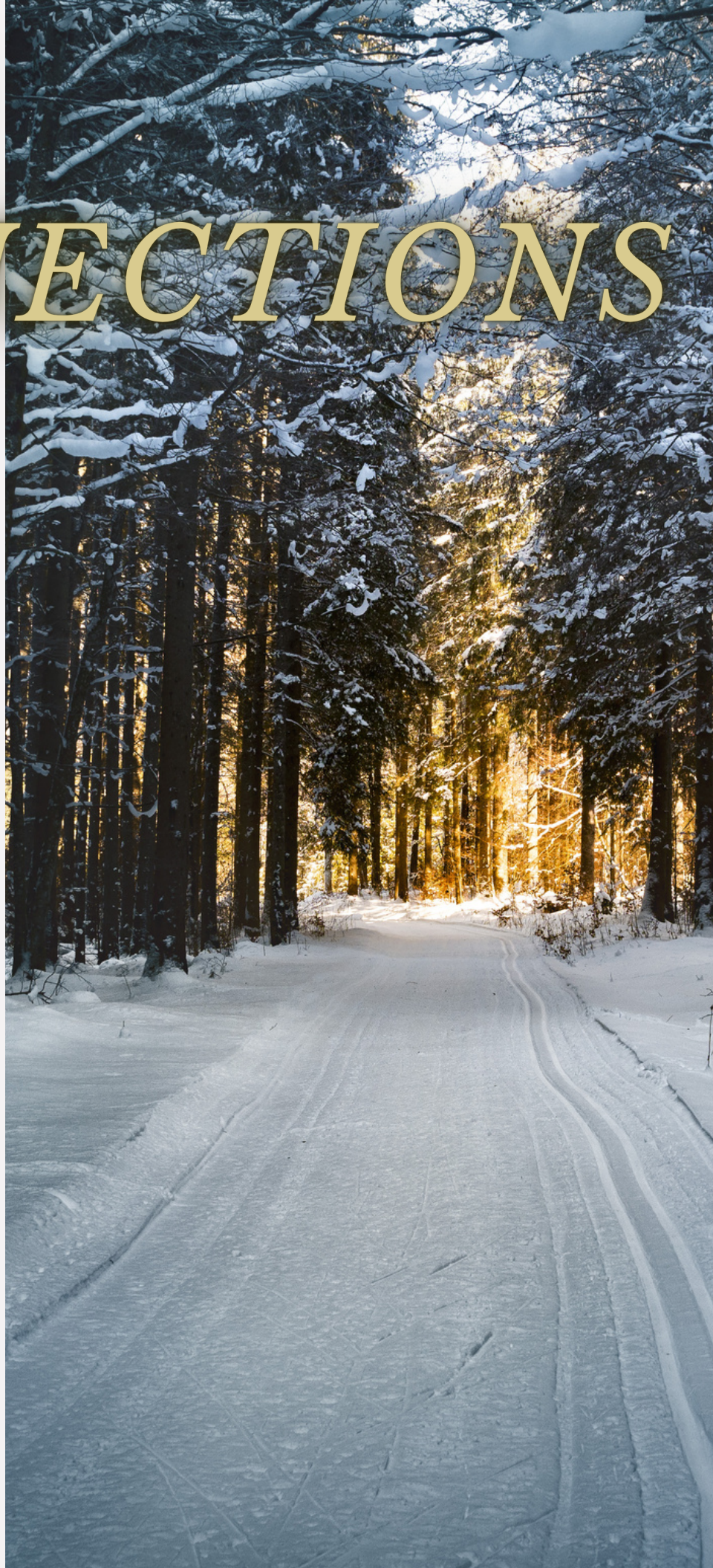
MDC CONNECTIONS

WINTER ISSUE 2021

Helping you maintain momentum with powerful resources is our priority.

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Welcome

Welcome to the first edition of *MDC Connections* — a newsletter series of resources to help you through these times of isolation. To inspire you to do more, to move more, to learn and to conquer. Empowering you and your loved ones with information and offering ways to connect.

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Please note that the listings below 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.



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

COVID *Connections*

This has been a strange and challenging year for us all, a maze of change and uncertainty. At times feeling so apart, and yet - truly - all in it together.

Remember how resilient you are, that you can and will get through challenging times, and perhaps find something that you never knew you needed.

On a day-to-day level we, at the Movement Disorders Clinic are here to support you through these times with resources and ideas to engage with loved ones, to try new things and to make new connections.

Our newly appointed and highly esteemed Clinical Nurse Specialist Keschey Marcelle offers inspiration, tips and suggestions:

Stay connected to the network you already have in place. Plan fun activities with the people you are living with such as board games, karaoke or a movie-marathon. Share a virtual physical activity - down the rabbit hole of YouTube!

Plan connections around a shared interest. Follow a TV show together and

then every week you have something to catch up on during your call.

Join a community that already exists. Many Parkinson's networks are offering creative ways to connect with their community such as group mindfulness sessions, yoga and exercise.

Check if your community is running safe socially distanced services such as weekly phone calls, walking groups, coffee groups, book-clubs and virtual support groups. Many services have virtual options for connecting such as boxing, dancing and singing.

It can be challenging to plan activities that fit in a range of energy levels, interests and abilities, but it's worth it - feeling supported by family and friends has been found to help reduce depression symptoms.

Encourage care partners, family and friends to find support and connections as well.

Remember to do things that bring you joy!

*"I can be changed by what happens to me.
But I refuse to be reduced by it"*
~Maya Angelou

We are grateful to have made it into your inbox, inviting you to connect in new ways. We are a small but passionate team and the feedback we receive from you makes everything worth the effort.

Here's wishing you and yours a healthy and restorative season. Please take these colder months and longer nights to embrace your own nourishing practices, to get more rest, to move a little more, and to reach out and connect with others. We all need it.

If you would like to provide *feedback* about this newsletter please [complete this survey](#) or email us at: movementdisorders@uhn.ca

Movement Disorders

Movement Disorders are neurological conditions defined by too much or too little movement. Some of these conditions such as Parkinson's disease (PD) are well known. There are several others such as Functional Movement Disorders (FMD), Dystonia, Tremor, Myoclonus, Tics, Ataxia, Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and other inherited conditions.

The Movement Disorders Clinic (MDC) was established in the 1980s. It has grown from a single neurologist to the largest clinic of its kind in Canada. MDC Faculty pictured below.

In this newsletter you will find links to resources that specifically mention Parkinson's. That is because there are a lot of resources tailor made to this condition - that doesn't mean that these resources may not be of benefit to other conditions. This and future newsletters will present resources and information suited to all Movement Disorders and even healthy older adults. We hope you find the information useful and applicable regardless if you have a diagnosis of Parkinson's, another movement disorder, are a care partner, a family member, friend, a health care provider or a combination.



Tech help!

This newsletter is made for technology! It works best if you view it on a computer, laptop or tablet. Links to resources are embedded. Anytime you see something **bolded and/or underlined** try clicking it to take you to a website. Happy viewing!

zoom is a must have. **Sign up** for a free account and join those meetings! Check out **this video** for instructions on how to join a meeting.

Virtual Visit help guides

For quick tips on how to prepare for a *virtual visit* at UHN check **here**. For more information click **here**.

Our clinic has a quick guide **here** and more details **here**.

Ontario Telemedicine Network (OTN) troubleshooting and help guides can be found **here**.



Parkinson's take note:

If you have **dyskinesia** it might be worse during a virtual visit, especially if you are nervous. Talk to your doctor if you have any concerns. It might be helpful to turn off your camera for a few minutes.

Move that BODY!

Exercise can help with *symptom management* and better *quality of life*.

Research results from the **Parkinson's Outcomes Project**, a **study** with over 13,000 participants spanning five countries show 2.5 hours per week of exercise can slow down the decline in quality of life.

The **Parkinson's Foundation** has many **resources** dedicated to get you moving!

Amp up your at-home workouts with these tips:

- 1) **Speak to a physical or occupational therapist**. They can tailor an exercise program to your needs.
- 2) Check out **Fitness Counts**. Read about the science of exercise, find tips and exercises you can do at home.
- 3) **Personalize a Fitness Friday video playlist**. Each video covers a movement disorders theme — from balance to boxing. Combine videos to create your own workout.

4) **Create a fitness space**. Set up a dedicated space with your towel, water bottle and a place for your laptop/tablet/smart phone.

5) **Work out when you feel your best**. Plan your workout around your medication schedule — ideally, when you feel the most “on.”

6) **Workout with a friend, spouse or partner**. Motivate each other to try new exercises, stay accountable and stick with it.

7) **Enjoy the benefits**. Regular exercise can help you sleep better and helps manage movement disorder symptoms and memory!







Visit the **Canadian Physical Activity Guidelines** for guidance on how many minutes of exercise per week you should do to maintain health and functionality.

Listen to
your body

Activity Guide

Try these!

Start
slow

	LOW INTENSITY	MEDIUM	HIGH
Aerobic  2 times per week	WALKING	ELLIPTICAL	<u>NORDIC POLE WALKING</u>
Strength Training  2-3 times per week	TAKE THE STAIRS	<u>BODY WEIGHT I.E., PUSH-UPS, SIT-UPS, SQUATS</u>	SHOVELLING SNOW!
Balance Training  2-3 times per week	<u>TAI CHI</u>	<u>EXERGAMING I.E., WII FIT</u>	<u>ARGENTINIAN TANGO</u>
Flexibility  2-3 times per week	<u>STRETCHING</u>	<u>PILATES</u>	<u>YOGA</u>

Check these out!

These days COVID has taken us for a spin, with many organizations pivoting to **virtual** — offering their exercise classes online. The silver lining is that you can try out classes not offered at your local gym. Many if not most are FREE!

Find one that you like and stick with it, try a variety of exercises from different sources, or simply do what you loathe the least!



Join the **Parkinson Association of Alberta's Motivation Monday** — streaming exercise classes you can do at home.

These programs offer a chance for you to stay connected and ACTIVE.

Check out their **YouTube channel**. Try this **PWR! seated class**.



The **Brian Grant Foundation's** exercise videos will take you through amplitude, flexibility, balance and cognitive training.

Have 20 minutes? Try this **aerobic and agility class**.



Join Colleen (she is fantastic!) from Beyond Fitness in Delray Beach Florida for **yoga**, and **Rock Steady Boxing** classes you can do **seated** or **not!** No gym equipment required.

Think *outside* the box!

Virtual activity doesn't have to be what we think of traditionally as exercise. The point is to get moving — in rhythm or out of pitch, give it a shot! You get what you put in.

Group singing has physical, emotional and social benefits. Interested? Check out Paula Wolfson's **Singing with Parkinson's**, they've gone virtual on zoom. No experience necessary, registration and fee required. For details contact dustydora@sympatico.ca



You don't have to have Parkinson's to participate. ALL ages and abilities can take part!

Want to become a better singer? Try **Jacobs Vocal Academy** for guided practice. Worth a try!



Dancing with Parkinson's offers FREE live daily classes

7 days a week. Get your dance on and reap the emotional, cognitive and physical benefits of dancing to music! Friends, family and care partners welcome. No experience necessary.

App Alert!

Apps are a great way to try out something new and connect with others. Be it a new activity, a zen inducing breathing technique, a therapy session, or a game you can play with your friends, family or even your grandkids. Challenge yourself and see where it takes you. You are more capable than you think!

For Activity:



PD Warrior -

Challenge your body and mind with this Parkinson's specific exercise program. Developed by specialist Parkinson's Physiotherapists. Recommended internationally by Neurologists.

For Wellbeing:



TeleCBT is an online counseling service specializing in

Cognitive Behavioural Therapy (CBT). OHIP covered. Register at telecbt.ca

For Relaxation:



Breathe - This app is a stress management tool. Learn how to perform and use diaphragmatic breathing techniques for stress control.

For Leisure:



NeuroNation - Brain Training & Brain

Games - 15 minutes per day of NeuroNation will give your brain new momentum. Join the online community. 7 day free trial. In-app purchases.

How are *you* feeling?

Written by Linda Redford - a care partner to her husband afflicted with Parkinson's for over 20 years.

A diagnosis of a movement disorder will bring on a wide range of feelings. There are many strategies to help you manage those feelings. Empathy and compassion are feelings we easily feel for others when they face adversity. It's important to remember that we are all part of the "common humanity". The human experience is imperfect; we all experience feelings of vulnerability. Sometimes we are tempted to equate vulnerability with weakness. Brene Brown has said; "Vulnerability is not winning or losing. It's having the courage to show up when you can't control the outcome."

The practice of self-compassion and acceptance are an essential strategy when things feel dark. Self-compassion allows us to have the courage to connect with family and friends and share our feelings.

Courage is from the word "coeur" or heart. It means to tell the story of who you are with your whole heart. Vulnerability isn't comfortable but is necessary for connection and authenticity. It's the willingness to do or engage in something where there are no guarantees. It takes courage.

Wholehearted people have the courage to be imperfect, the compassion to be kind to the self-first, then others. Recognize that it is the movement disorder that is imperfect and that you are authentic, courageous and marvelous. Let go of who you think you *should* be and instead be who you are!

*Vulnerability is
uncertainty, risk
and connection.*

Asking for help is strength. Sharing my condition with others is strength. When I ask for and accept help not only do I benefit but the other person feels wanted and useful. The opposite of asking for help is isolation. Family relationships and friendships are bonds built over time on mutual trust. John Gottman found that trust is built in small “sliding door” moments. Embedded in those moments are opportunities for connection.

Positive relationships and a supportive environment play a role when it comes to facing adversity. The joy, humour and comfort we experience with friends contribute to better health and a more positive outlook on life.

Positive relationships contribute to a lower stress level and increase our ability to overcome challenges. What do you need to do to give yourself permission to connect with others in spite of any feelings of vulnerability? What do you need to do to give yourself permission to create a personal support group?

What does support look like for you?

REFERENCES

Brown, B. (2008). I thought it was just me (but it isn't): Telling the truth about perfectionism, inadequacy, and power. New York: Gotham Books

Brown, B. (2012). Daring greatly: How the courage to be vulnerable transforms the way we live, love, parent, and lead. New York: Gotham Books

Brown, B. (2015). Rising strong. New York: Spiegel & Grau

Core Values List: Over 50 Common Personal Values.

<https://jamesclear.com/core-values>

Resiliency Resources

Reading

The New York Times series on resilience illuminates learning opportunities in troubled times. "Finding emotional support during a crisis often means turning to long-established networks already built for distance."

Amidst uncertainty, we have gained clarity on the connections that matter to us most. Read on for personal anecdotes: 8 Ways the pandemic has strengthened relationships. Thrive Global

What resilience means, and why it matters. Harvard Business Review uncovers resilience in the business world is dependent on three things — staunchness, making meaning out of hardship and improvising solutions.

Watching

In this **TEDx** talk The three secrets of resilient people, Dr. Lucy Hone director of the New Zealand Institute of Wellbeing & Resilience shares her insights on human suffering after going through an unimaginable tragedy.

Resilience: The key to success in the face of adversity webcast by the Canadian Management Centre shows that resiliency can be learned and improved with practice. Learn strategies and tips for how you can master your mindset and boost feelings of optimism.

Resiliency is the ability to adapt to stress and adversity.

Research Round Up

COVID-19 has forced us to take a pause. A long pause. But Parkinson's hasn't slowed down, it affects *6 million* people worldwide and is projected to double in the next decade.

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



You may have seen our very own Dr. Lorraine Kalia in the news [here](#) and [here](#) recently, showcasing her work on focused ultrasound for Parkinson's.

If you're interested in taking part please ask your doctor to fax a referral for FUS (Focused Ultra Sound) clinical trial screening to the attention of:

Dr. Nir Lipsman at Sunnybrook at
416-480-6085 (fax)

or

Dr. Lorraine Kalia at UHN at
416-603-5004 (fax)

If you fit the criteria you will be contacted by a member of their research team within 4 to 6 weeks.

→ We have several clinical trials that are actively looking for participants with a diagnosis of *Parkinson's* and are *not* taking any medications for it.

→ We are also looking for participants with:

- *Parkinson's*
- *MSA (multiple system atrophy)*
- *PSP (progressive supranuclear palsy)*
- *Friends or family members*

Willing to come to the clinic for spinal fluid collection and a skin sample.

→ Our *Cannabis* study is in full swing. If you have bothersome pain and are interested in hearing more, contact Deborah at 416-603-5800 ext. 3684 or deborahmancini@uhnresearch.ca



We have lots going on! For a list of research studies **[click here](#)**. If you fit any of the criteria or are interested in other opportunities you may contact our general email address **movementdisorders@uhn.ca** and a member of our research team will be in touch with you.

You can move
research forward.

Recently in the *NEWS*

Mind control: Toronto doctors regulate patients' brains from afar using electrode stimulation



cbc.ca

Toronto Western first to use new Percept medical device



Multidisciplinary care for Parkinson's Disease: building a program with patients as partners

Toronto General & Western
Hospital Foundation  UHN

UHN Parkinson's Disease researchers co-lead world-first study

Toronto General & Western
Hospital Foundation  UHN

Focused ultrasound opens blood-brain barrier for Parkinson's patients

 TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

Toronto team uses ultrasound to deliver Parkinson's drug directly to patients' brains



The Doctor would like to see you for a follow up

Written by Melinda Davis

"The doctor would like to see you for a follow-up," said the reception on the other end of the telephone line.

I knew it was bad. I would spend the next three nights, sleepless. Three days of overwhelming anxiety until my appointment.

What are they going to tell me? Maybe the neurologist forgot that he told me he would only call me if my test was positive? Why did he tell me that? Why did he call? I knew why several weeks ago, the day I ran for the streetcar and my leg started to spasm.

A few months ago, I went to a new general practitioner who happened to be my mom's doctor. During our meet and greet she asked me if I had any family illnesses. Before I could respond, she answered her own question:

"Oh yes, Spinocerebellar Ataxia," she said.

"What?" I ask.

"Oh, don't you know?" she asked surprised by my response.

"Apparently not," I replied.

"I hope your mother won't be mad at me. I think you should talk to your mother," she said.

I told the doctor not to worry, that I would not throw her under the bus.

"Yes, I will talk to my mom."

When I got home and my mom asked me how my doctor's visit was, I told her it was great. I really like her. And she asked about family illnesses.

"Oh, did she mention Spinocerebellar Ataxia?" she asked in a chipper tone. "I have it and I've known for five years."

WHAM!

A punch to the gut.

Sitting across from the woman that gave birth to me, my rock, the one who kept it together when my dad wouldn't come home for days, the funny one, the giver. The one that had lied to me for five years. The one I now hated.

I knew what it was without knowing the name.

My grandmother couldn't walk very well and choked on just about everything. She shook and trembled but that was normal. Doctors didn't know what it was because there was no name for it. So my Italian family just hid that there was anything abnormal and went along.

Then my uncle got sick. He started to tremble and shake and eventually couldn't walk or talk. But the doctor didn't know what it was, even though there was a name this time. Misdiagnosed.

Until now.

Five years ago my mom started to get clumsy and dizzy. She went to the doc and mentioned what her mom and brother had experienced. Doc sends her to a neurologist and WHAM.....it has a name! The ugly disease has a name!

So for 5 years mom keeps it to herself. Because if you don't tell anyone maybe it will just go away. Or not exist. Even though the geneticist recommended she tell her kid, as it is hereditary.

I get it. Not telling. Why do you want to tell someone, I'm sorry, I have a faulty gene that I may or may not pass on to you. It will be a slow and arduous decline. You eventually won't be able to walk or talk and have a nice day.

But if you don't acknowledge it how are you supposed to accept it? To fix it? To be part of a solution? Knowledge is power.

The day of my new doctor's visit was the start of a lot of crying. Crying myself to sleep. Crying when I woke up. Crying in the bathroom at work. And a lot of self-reflection.

What would you do if you could take a test that would tell you if you have a disease that will eventually kill you? Guess what. There is no right or wrong answer. It's all a matter of what you want to know and can deal with. I agonized over whether I wanted to know. I lost sleep. When I tripped or dropped something I already had it in my mind. I listened to my friend's opinions about wanting to know or not.



In the end it would be my decision. I decided that if I didn't know that I was a carrier of this faulty gene that I would drive myself crazy not knowing either way.

I decided to take the referral to the neurologist. And I felt sure in my decision and no one was going to try and tell me otherwise. My mom was not favorable of my decision.

The day of my appointment was fine. I brought a girlfriend for moral support. Had a bunch of neurological tests done and in the end the doc says 'I don't think you have it. You have no symptoms'. 'But the true test will be the blood test'. 'I tell you what, I will call you to tell you it's negative'. I wish he wouldn't have said that but I know he meant well.

This is no regular blood test. It's genetic testing. Two months of waiting for results. Two months of forgetting what you're waiting for. Trying to forget.

After the phone call inviting me for a follow up, I had 3 days to wait. It was an agonizing 3 days. I brought my husband and the same girlfriend with me to the neurologist.

The first thing I said to him was that I was expecting a phone call. He said he was sorry, that he thought he would only need to call. I was positive. Positive for a bad gene. A mutated gene. I thought this would be a good name for a punk band. *The Mutated Genes*. And I would be the angry lead singer.

This day would be the beginning of another period of crying. Feeling sorry for myself was an understatement. How could anyone even possibly say anything to me to cheer me up? How could anyone understand how I was feeling?

But I wanted to know.

And after a period of mourning I decided that I could either spend my life feeling sorry for myself or look at things differently. Positive thinking is more powerful than this disease.

My head is not stuck in the clouds when it comes to the reality of what may lie ahead, but why get stuck in negative thinking? This is already such a negative thing, why give it any more.

I was diagnosed with a disease I have no symptoms of right now. It doesn't make me feel better knowing what may inevitably happen. I have two kids and there is a good possibility one of them will inherit it. They are a little too young to understand what a neurological disorder means so I have spared them the information for now. Will I tell them? You bet. They have a right to know.

Knowledge is power.

You can support Melinda's fundraising initiative for the Toronto Western Hospital Movement Disorders Ataxia program [here](#).

Ataxia is defined as a loss of voluntary motor control and is often used as an umbrella term to classify a group of diseases that effects movement coordination.

Ataxia can affect all age groups, with the age of first ataxia symptoms varying widely from early childhood to late adulthood.

Ataxia Resources



[National Ataxia Foundation](#)



[Ataxia Canada](#)



[Friedeich's Ataxia Research Alliance](#)



[Living with ataxia](#)



[SCAsource](#)



[Rare disease registry](#)

If you would like to tell your story or be interviewed you may email movementdisorders@uhn.ca

Patient Advisory Board

I am pleased to introduce you to your Movement Disorders Clinic Patient Advisory Board (the “PAB”) here at Toronto Western Hospital and their work so far. Your PAB is currently made up of patients with Parkinson’s Disease including Young Onset Parkinson’s, Dystonia, Atypical Parkinsonism’s, Ataxia, and Functional Movement Disorders. In fact, you just met two of your members reading this newsletter, PAB members Linda Redford and Melinda Davis.

We each humbly work to represent your voice as one of thousands of TWH Movement Disorder Clinic patients and their families.

Our mission is to advise faculty (the Docs) and staff on innovations in clinical care, education & research with the intent of improving the patient experience, communication and the quality of research conducted within the Movement Disorders Program at TWH.

Sounds nice, what does it mean? In 2021 the PAB will work with faculty and staff to:

- Reach a large number of you, in ways we have never done before, with information you can put to good use now! We are starting with this newsletter, developing your [TWH Movement Disorders Clinic website](#), and posting on a Facebook page [@TWHMDCPAB](#) and on Twitter [@IntegratedMove](#).
- Figure out how to get the 70% of you who say you are interested in research to involve you more - from enrollment in studies through to finding out what the research learned. We are starting with a Clinical Trials 101 package, presentations by patients on what it’s like to join a study, and surveys to find out what gets in the way. By year end we will start up a group of clinical research ambassadors - real patients and families here at TWH to help you along the way.

- We are very excited about our Integrated Movement Disorders Program pilot. Your PAB will give advice to the team as it moves from learning from its first group of patients to piloting the treatment approach in your local communities. More on this program in coming newsletters.

By the end of the year, we will also start up a group of in-clinic patient/family ambassadors focused on making your experience better.

Your PAB is a group of volunteers looking to have an impact for you “as the patient” and your family in practical ways that otherwise might not have happened. PAB members are people just like you! As one of our members said “there ain’t enough of us to go around.”

If you are interested, we will need people to work as patients & family members with faculty and staff, to “get things done”. If you are interested, please let your clinician know and they will pass your contact information along with your consent.

I had the honour in 2020 to meet some amazing TWH MDC patients and family members, and look forward to meeting more of you in 2021.



Hugh Johnston, CPA, CA Retired
Chair TWH MDC PAB



COVID Resources



What's open, what's not. Check for the latest news and updates on services, appointments and requirements. Have a virtual appointment? Know what to expect.



Stay informed. Know when, where and how to get tested and when to stay home.



For current news, restrictions and guidelines to keep you safe and in-the-know.



How Ontario is responding to COVID-19. Includes case data, testing locations, and a self assessment tool.



Toronto Public Library is here for you! For entertainment, boredom alleviation and endless learning. You don't need a library card to access their wealth of resources.

VIRTUAL HUGS



#StopTheSpread

STOP THE BUGS

In turbulent times
you can ***reset your nervous system*** by:

- 1) **Bringing to mind** a place, person, pet, or strong personal quality that gives you strength or joy.
- 2) **Holding** that resource in your mind's eye while paying attention to the pleasant sensations.
- 3) **Noticing** your slowed breath, heart rate and relaxed muscle tension.

Source: 3 Ways to Harness Resilience During Turbulent Times

You are not alone.

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email us at: movementdisorders@uhn.ca