

Parkinson's Support Group of Sudbury

Meeting Notes

June 16, 2021

There were a total of 19 of us in attendance as Wayne welcomed everyone to the last meeting of this season. We are taking July and possibly some of August off and as before the pandemic, there will be no meetings in those two months. Unless someone else would like to host a gathering (a Zoom gathering, of course) on July 21 and/or August 18. The Zoom link would remain the same as the one you have been using, and the time slot is reserved for us if we would like it. It is up to you. Contact Nora Lea if you would like to volunteer to "host" a meeting.

Superwalk 2021 – Richard Carriere updated us on the plans for Superwalk on Sept. 11, 2021. Since Parkinson Canada is asking us to still refrain from in-person gatherings, Superwalk will be conducted as last year, with small family groups walking in their own neighbourhood. To make it more visible there are "Walk-in-a-box" items, such as iron-on transfers that can be used on T-shirts. Or you can wear T-shirts from previous year's walks, whatever you would like to do.

Registration online through the website www.superwalk.ca is the preferred method and as much as possible they encourage us to invite our supporters to contribute through that website. If you have any problems setting up your "page" on the site, Alejandro is available to answer any questions and "chat" online or on the phone to solve your problem. One nice thing about donating online, your supporters receive their receipt right away, attached to the response that acknowledges their gift.

While it will be different from the energy and enthusiasm and fun that comes with the larger gathering at Delki Dozzi Park, it can still be a lot of fun. Open air gatherings are probably still the safest and depending on the Public Health restrictions at the time, we can gather a number of friends and family to walk in our area with us. Weather permitting of course (we do live in Canada!):



Wayne was able to share his screen and show us how to get into the Superwalk site and begin the registration process.

Richard explained that he and Louise have found adding a personal message to your request for support goes a long way to increase the donations under your name. If you are going to email directly from the site, you can personalize the actual request for donations.

Richard also attempted to stimulate a little friendly rivalry among the SuperStar walkers from the last couple of years and suggested we get a start on seeking donations from family & friends if we wanted to beat Bruce in his fundraising. Garry said that he & Cindy found it takes a second email or message to remind people, as they tend to leave it to the last minute. This is the big fundraiser for Parkinson's Research, and we want to make the most of it!

Upcoming Events:

Davis Phinney Foundation - Charting your course: a Parkinson's primer for the newly diagnosed Young Onset (YOPD), Victory Summit Sat. June 26/21

Be prepared to be inspired, uplifted, and challenged (in a good way). Whether you're newly diagnosed, or have been living with YOPD for a while, there will be something here for you. Learn from and interact with Parkinson's experts and people living with YOPD. From the biology and etiology of YOPD to treatments, reinvention, exercise, and more, you'll leave with a concrete plan on how to live well with Parkinson's for many years to come.

God didn't remove
the Red Sea, He
parted it.

Sometimes God
doesn't remove your
problems, He makes
a way through them.

<https://davisphinneyfoundation.org/the-victory-summit-virtual-event-yopd-registration/>

TIPS FOR BITS

With no Tim-Bits in sight, Nora Lea still shared a tip for entertaining conversations with your grandchildren: <https://momhacks101.com/101-fun-questions-for-kids/> These are designed to draw out more than the usual one-word response "fine" or "duh" to questions like "How was your day?" There were some good ideas here and with our kids spending so much time on computers and in front of screens, this suggests a way to change that.

By the way, Shawn Pitzell, the Audio-visual technician at All Nations Church who has been assisting the group with microphones and computer connections for years, is retiring. Wayne made up a Certificate of Appreciation, framed it nicely, and presented it to him today along with one of the stained glass tulips (made by Brenda's dad) and a thank-you note expressing our appreciation for his sacrificial service to our group over the years. No matter how busy he was, Shawn always took the time to make sure our mics were working and the computer hook up to the big screens was functioning before each meeting. He seemed quite touched by the presentation. There was a little staff-party for him at the church and Wayne took the opportunity to make the presentation at that event.



Opinions sought regarding exercise classes during the summer:

Since the numbers at exercise classes tend to fluctuate during the summer, we wondered if we should continue at three days a week in July & August or if we should go down to twice a week. It seemed that most people preferred twice a week. With the Covid restrictions lifting people are anxious to get together with their families and to be outdoors, not indoors. Final Decision: Tues. & Thurs. during July & August (we had already chatted with Denise).

Learning the Parkinson Lingo – A discussion style terminology review:

When someone is newly diagnosed and hears us talking about Parkinson's, the words we use can be somewhat baffling. During this meeting we will try to dispel some of that confusion and clarify what is meant when we use those fancy words. There was great discussion involving all participants and lots of stories shared regarding various experiences with these issues.

ON - when the medicine IS working and your symptoms are better.

KICKING IN – the process of meds starting to make a difference – some people notice, some don't.

OFF - when the medicine is NOT working or has worn off and symptoms return. Sometimes we notice a dose is not working, called a failed dose. Can be due to dietary protein with the med or possibly constipation is interfering with absorption.

WEARING OFF – the process where the meds start to lose their effectiveness. Can be quite uncomfortable at times.

TREMORS - the shakes; commonly seen as diagnostic of Parkinson's Disease but 30% don't have it. In Parkinson's Disease a "resting tremor" is often seen, usually beginning on one side.

RESTING TREMOR – occurs at rest, often affects thumb & index finger giving a "pill-rolling" effect,

INTERNAL TREMORS – can be an internal vibration, or feel like worms crawling under the skin.

RIGIDITY – Often referred to as cog-wheel rigidity. It is when you feel like you are in a body cast, or feel that you are "fighting your jeans" as you try to walk or move.

DYSTONIA (dis TOE nee uh) - those severe cramps you may get, like a charley-horse, it grabs and won't let go.

FREEZING – (AKINESIA) – often referred to as FOG (freezing of gait) when you want to move but can't, or when you are moving and suddenly don't. It may feel as if your feet are set in cement and can't move another step (your upper body may not get the message that the feet have stopped and the body keeps moving forward; often the cause of falls)

BRADYKINESIA -(BRADY ki NEE zee uh) like you are in slow motion, "if I go any slower, I'll be going backwards!" Judging the time it takes to do something is "off" because of the slowness. "Parkie time."

DYSKINESIA - (dis ki NEE zee uh) those rhythmic, almost twisting, movements (think, Michael J Fox) that are a side effect of the dopamine meds after 7 or 8 years or of 7 – 8 years with the diagnosis. (new research! [click here for the WPC Report](#))

HYPOKINESIA – you seldom hear this word used, but one of the first symptoms often noticed is decreased number of spontaneous movements, such as arm swing, blinking, swallowing.

POSTURAL INSTABILITY - when you can't maintain your balance (turning quickly can lead to a fall) or body position (you may find yourself tipping forward, or toppling backward when going up stairs)

VERTIGO – dizziness, disturbance of equilibrium. Quite different than postural instability but it may contribute to it. Certain types of vertigo can be helped with Epley's Maneuver administered by a physio, chiropractor or physician.

MASKING - when your face no longer shows emotion. You have to choose to smile.

MICROPHAGIA – small handwriting; It may start out normal size, but gets smaller and smaller as you go across the page.

RETROPULSION – walking backwards (if you can't stop it, at least aim for where you want to go 😊)

PROPRIOCEPTION – awareness of your body position in relation to time and space

FESTINATION – a walking gait characterized by involuntary acceleration, usually short, shuffling steps that get faster and faster.

ORTHOSTATIC HYPOTENSION – low blood pressure related to sudden changes in body position (from lying to standing, sitting to standing). Levodopa itself can lead to low blood pressure, as can a large meal. If it becomes a serious problem, there are pills to raise blood pressure, or you can try to raise it by increasing salt and fluid intake.

DOPAMINE – the chemical in our brains (neurotransmitter) that is reduced in Parkinson's disease, due to the death of the brain cells that produce it. Levodopa, the medication most frequently used in PD, is a dopamine precursor that is converted to dopamine when it reaches the brain. Usually very effective at improving motor symptoms. Referred to as the Gold Standard of Parkinson's treatment.

DOPAMINE AGONISTS – a group of drugs that mimic the action of dopamine by binding to the dopamine receptors in the brain. Generally used early in disease or later on added to levodopa regime. Have been cited as causing Impulse Control Disorders in some people (shopping, sex, gambling addictions), which stop as soon as the drug is stopped. Dopamine Agonists must be weaned off slowly.

MOTOR SYMPTOMS – symptoms that have to do with movement

NON-MOTOR SYMPTOMS – symptoms that have to do with systems other than movement, the autonomic nervous system

COGNITION – the way we think or process information

COGNITIVE IMPAIRMENT – when our thinking isn't quite as sharp as we'd like: memory loss, forgetfulness "what did I come into this room for?" Multi-tasking becomes challenging.

DEMENTIA – NOT the same as Cognitive Impairment, "I can't find my keys" vs. can't figure out what to do with the keys. Involves memory disorders, personality changes, impaired reasoning. Click [What is Dementia?](#) for a very good brief description.

HALLUCINATIONS – part and parcel of the disease, one of the symptoms that MAY appear, they are not usually troubling, just "there". If they do become scary or impair the quality of life, there is help available. Usually involve children, animals or people.

ILLUSIONS – a misinterpretation of a "real" visual cue. A sweater thrown on a chair might be mistaken for a cat.

DELUSIONS – false beliefs that conflict with reality. Delusions are often reinforced by the misinterpretation of events. Many delusions also involve some level of paranoia.

PARANOIA – fixed false beliefs that usually involve someone acting against the person; may have suspicions that someone is stealing from them, or a common one is that the spouse is cheating on them. IF it happens, there is help. Talk to your doctor!

Nothing like ending on a "downer". **Fortunately, not everyone gets everything!**

Still no Tim Bits – but Garry shared his best tip: "Make adjustments as required. 😊
Have a great summer!