Oct. 20, 2021

Welcome everyone! A Question of Safety

Yes, our meetings are still virtual and we are not pushing to change that just yet. We did give it some serious consideration when we were trying to plan a Christmas Party and thought how nice an in-person gathering would be.

After giving the matter some serious thought and re-reading the guidance from Parkinson Canada, we did not feel comfortable with the idea of planning a party for December when we haven't yet seen the fall-out from Thanksgiving gatherings. I called Donna Greening of Parkinson Canada for some frank discussion on whether or not we should push for some inperson gatherings.

Here are some notes from that discussion:

- Parkinson Canada has recommended there be no in person meetings for the time being.
 They will revisit the decision to hold in-person meetings in January of 2022.
- We have not yet seen the effect of the Thanksgiving gatherings. What will those stats reveal about the risk of transmission?
- How would we feel if we took it upon ourselves to resume in-person meetings and someone got sick with and possibly died from Covid?

Donna's husband developed Covid during an outbreak at his workplace where 12 staff became sick. He had received his shot a day or two before exposure to the virus. There was not enough time for his body to develop an immune response. He was quite ill with Covid and the fatigue was overwhelming. He also discovered that the loss of the sense of smell and taste is more concerning than you might think. He can't smell smoke (if the house was on fire), or smell if there was a gas leak, or if some food has gone bad. At one point, Donna gave him a drink of "water" (actually vinegar) and he drank it with no reaction at all. That really scared her. Now, five months later, his sense of smell and taste is starting to return, the tremendous fatigue is abating and the "brain fog" is clearing. The brain fog was also very scary for Donna, as she had no idea if it would clear or remain.

Some of his co-workers experiences with Covid:

- One had to learn to walk again
- One, at age 43, is expected to never work again
- One had to be transferred to an ICU in St. Thomas, ON because there was no bed for him in Winnipeg.

Is this anything we want to see happen to anyone in our support group? If it did, would we really think "It was worth the risk" because we needed to meet in person? I know the donor of the money for the party would not.

On the basis of all that, and more, Wayne and I both feel it is not worth the risks involved to have an indoor in-person event. If a couple of members want to meet face to face, that is one thing, they can weigh the risks individually, do their own screening and determine their own comfort level. Just as we did the other day, to hold the leadership team meeting.

The exercise program at the Parkside Centre resumed their in-person events on Oct. 18. Since this is not Parkinson Canada sponsored, their protocols don't apply. The Parkside have their own protocols in place and the program is offered in a hybrid format, meaning that you can attend the class in person or via Zoom. Same class, different risks. You choose.

Covid-19 is not at all nice and we want to do our part to avoid it among our group members. Yes, we may be missing out on making contact with some newly diagnosed people, and for that, I feel bad, but I'd rather take the risk of delaying contact to avoid the risk of Covid.

All that to say, "No, no party, not for now." HOWEVER, If anyone would like to be part of planning a Virtual Party (something along the lines of what we did last year), there is an opportunity awaiting you! Just call me, Nora Lea, 705-522-3321.

Superwalk Report – from team captain Richard Carriere. We are down just a little, last year the total was around \$20,000, this year \$18,439 (and counting). Louise's Trekkies raised \$6,049! Some of the off-line donations have finally made it into that Sudbury total. The money raised at SuperWalk funds research, provides educational materials, and permits Parkinson Canada to act in an advocacy role on behalf of people with Parkinson's. Well-done everyone! Thank you! Alejandro (our concierge at Parkinson Canada Superwalk) says *CONGRATULATIONS*, *Richard and everyone in the Sudbury community*. Although we had more minor registrants this year, we are still showing the world that Parkinson's will not stop us from coming together and raising our voices, NO MATTER WHAT! It makes me proud to know how strong and committed our Superwalk folks are to everything we do. I appreciate you for all that you do for the community and for always allowing me to support you in any way possible.

Christmas Cakes and Cookies:

You know you've hit on a good, sustainable fundraising tool when people start coming to you and asking when you are going to start selling. Several of our vendors have been looking for "product" and renewing their commitment to support our group by selling our Christmas Cakes and Cookies. You can have a part in this great fundraising effort, by offering them to your friends, families and coworkers. This is how we fund the exercise program and the Support Group activities.



CAKES (dark, light, cherry) \$20

COOKIES \$10

PLUM PUDDINGS (with sauce) \$15

Get your order in now! Sales are first-come, first-served. We have submitted our order to Grant's Bakery (Quebec) based on the quantities sold last year, and we will not be submitting a second one. If you start taking orders now you'll be ready when our inventory comes in. Order forms will follow, or just call one of our team captains. (next page)

Team Captains: Claire Sheridan 705-522-9682, Brian Matthews 705-522-3495 (Brian sent his regrets that he was unable to attend this meeting. He is in the middle of moving and had another appointment that conflicted.) Ray & Myrna Levac will also take orders 705-560-5169.

Our Other Sales Venues

Falconbridge Legion Fish Fry – Nov. 5th – JoAnne McNamara & Erin will be helping out Giant Tiger – Nov. 19-21st – George & Denise Black – need someone to spell them off? Biancos, A & J Home Hardware, Jim's Automotive, etc. (not sure about Deluxe yet) . . . and more

Educational Events: If the date has passed, the recording will be available shortly.

Oct. 25 at 6 – 7:30 pm, **Advanced Parkinson's Care and Estate Planning** In this session, you will have the opportunity to hear from:

- ❖ Dr. Sean Udow, Assistant Professor, University of Manitoba, Neurologist, Movement Disorders Clinic, about the needed care for the advanced stages of Parkinson's
- ❖ A member of the Parkinson community on how they deal with the demands that the advanced stages of Parkinson's brings
- ❖ Erin Bury, Co-founder and CEO of Willful, who will explain the ins and outs of Estate Planning (and why you should care).

(I just have to watch this part, who has a job so aptly related to their surname?)

Oct. 26, 12 – 1:00 pm – Hearing and Cognitive Health: Reducing Dementia Risk and Optimizing Functioning and Care

(recording is ready)

A man was telling his neighbor, 'I just bought a new hearing aid. It cost me four thousand dollars, but it's state of the art. It's perfect.'

'Really,' answered the neighbor. 'What kind is it?' 'Twelve thirty.'

Half of Canadians will have a hearing loss by 75 years of age. Hearing loss increases the risk of cognitive decline and dementia. Those with combined hearing loss and cognitive impairment are at increased risk for declines in everyday functioning and entry into long-term care. Importantly, hearing loss is the largest potentially modifiable risk factor for dementia. This presentation will

describe the connections between hearing loss and cognitive decline, with an emphasis on what could be done to help reduce the risk of dementia and optimize everyday functioning and care.

Nov. 3, 6:30-8:00 pm – Stimulating Brain Discussions on DBS: Considering DBS, Dec. 8, 6:30-8:00 pm – After DBS

https://events.myconferencesuite.com/DBS PatientEd 2021/reg/form/edit from the Movement Disorder Clinic at Toronto Western Hospital, University Health Network

"Every Victory Counts" Canadian Edition

This is a new offering from Parkinson Canada in collaboration with the Davis Phinney Foundation. A positive and encouraging resource. Sign up now to receive a free printed copy early in 2022 or a digital copy anytime. https://www.parkinson.ca/gated/every-victory-counts/ Updated stories of resilience and strength along with Canadian content, research and sources of help.



Introducing a couple of our Resources:

Parkinson's Disease - An Introductory Guide

This guide will help you better understand Parkinson's disease. It describes the illness, changes in your body over time, treatment and care options, possible health problems, as well as when and where you can find more help.

When you are trying to determine if a particular symptom is Parkinson's related or might be due to something else, it is a great reference book as it lays out symptoms in a simple straightforward manner. If you know what can reasonably be expected in Parkinson's Disease, when a new symptom crops up you will have a tool to help you identify if it is PD. Of course, you will follow up with your GP or local neurologist, but you will have a sense of comfort that it is not time to panic. Drippy nose? Panic: Covid? Reasonable expectation: Parkinson's.

Pamphlet: Progression of Parkinson's Disease -

This is a quick summary and can help you get an overview of the disease. You might want to keep it handy for quick reference. The front page is the shortest summary I've seen and it's good. https://www.parkinson.ca/wp-content/uploads/Progression_eng_PC.pdf

Wearing Off & Dyskinesias -

As the disease progresses, the longer we have it and the longer we are taking medications for it, the more likely we are to run into problems with "wearing off" and "dyskinesias". Louise attended a webinar on this topic recently and she found some helpful tips from the panel. Her review is attached. It is a bit tricky to make notes on a panel discussion, but she did it!

Exercise classes at the Parkside Centre "Parkinson's Mobility Program"

Mondays at 1 pm, Thursdays at 2 pm.

We are working out the kinks – conducting the exercises in person and over Zoom at the same time. If you would like the Zoom link, email Natalie Labbee at the Parkside to register:

Natalie.labbee@greatersudbury.ca

Attending in person:

- You will need a mask for the common areas
- Please bring your own exercise band
- Bring your own water bottle, if possible

Attending on-line:

- Have something you can use for hand-weights (2-lb)
- Could be 14 oz. soup can

Next Meeting – November 17 (& Virtual Christmas Gathering Dec. 15)