

Parkinson's Support Group of Sudbury

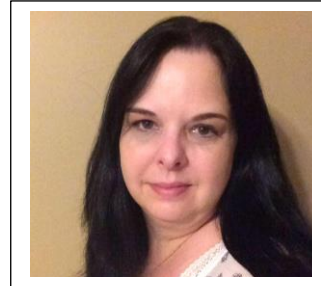
Meeting Notes May 19, 2021

Welcome to everyone who was able to be "here". Regrets from Louise & Richard, and Claire.

Special Guest: Donna Greening, Community Engagement Coordinator with Parkinson Canada.

Attached is a handout with links so people can register or check out things that interest them:

- Webinars
- Parkinson Advisory Council
- PD Awareness Month
- Social Media
- Information & Referral team continuing education
- Fundraising initiatives
- C-OPN "



A big "Thank you! to those of you who volunteered for the projects we are undertaking:

- A photo-book history of the group – Claire Sheridan & Louise Picard will tackle this, Nora Lea had fun researching the history through old files and records. Lots of history of shared activities: we've worked together, learned together, played together and even partied together!
- Telephone Connections – Francine Luoma & Marianne Bech (to touch base with various members, particularly shut-ins) have agreed to take this on. I'll be working on "cleaning up the list" as my next project before passing the torch on to them.
- Our Facebook page, making the most of it – Cindy Shyminsky is doing a great job.
- Our Group website – Brian Matthews, hopes to have some time this month to put in more work on this. It's a work in progress.
- A Welcome team for newcomers. (someone to call and chat and offer resources from our resource cupboard, as well as share their own experience with Parkinson's Disease.) Anyone wish to volunteer?

Superwalk 2021 – the website opened May 4th! – Richard Carriere & Claire Sheridan will be the Coordinators once again. You may start now to get registered and write up your story.

Parkinson Canada Resilience Webinar: Perspectives on Living Well with Parkinson's: No Matter What. (Thurs. Apr. 29) Donna already talked about this one. Excellent speakers! In case you missed it, Parkinson Canada closed off this year's Awareness Month with a webinar on the topic of Resilience. Many thanks to Tim Hague Sr. for being our keynote speaker (winner Amazing Race Canada), to our wonderful team of panelists for sharing their stories, and to our CEO Dr. Karen Lee for moderating the discussion. Watch it at any time [here](#).

One of the things highlighted in this Webinar was attitude. A little "attitude adjustment" I picked up at the 2013 World Parkinson Congress in Montreal, PQ:

Illness – starts with "I" ("I, me, my" = depression);

Wellness – starts with "We."

For your own "Attitude Adjustment," just watch this clip from Brian:



Attitude.mp4

Many thanks to Brian for sharing this with us. The group seemed to really appreciate this.

Have you got your Covid-19 vaccine yet? Don't know which one to get? Allan Jones, Sandie's husband, sent us a couple of YouTube clips that may help you to understand the differences in vaccines and their efficacy rates. (Spoiler alert: the one to get is the one that goes in your arm 😊)

<https://www.youtube.com/watch?v=K3odScka55A>

<https://www.youtube.com/watch?v=V4cyYvmU5Cc>

They aren't too long, one is 7 minutes and the other is 4+ min.

Upcoming Events:

May 20 @ 1:00pm – Myths & Facts about Levodopa (World Parkinson Coalition) if you can't attend but want to hear the information, register anyway and they will send you the link to the recorded session when it is ready.

You may have noticed a plethora of events coming your way from many different organizations. So much so that I feel bad sending them out to you, not knowing if you already receive their mailings. If there is a particular group that you have an affinity for, perhaps it wouldn't feel so overwhelming if you subscribed to just that one. I can give you a quick overview of what I think is the difference between them. Please chime in with your thoughts. Everyone agreed that they did appreciate getting this information and would prefer to get it twice rather than not at all. Asked if they would like to receive a summary of the differences between the different organization's way of delivering information. They agreed, "yes".

Organizations that offer usually reliable information:

People will gravitate to the format of information-sharing that suits their personality.

- **World Parkinson Congress/Coalition** – Everything they offer is based on scientific studies, some are cutting edge and some are exploratory or controversial. Usually suits the scientific mind-set.
- **Parkinson Canada's offerings** are reality based, usually scientifically based and practically applied. They have begun to broaden the scope of subjects covered to include not just the symptoms of Parkinson's Disease, but also the reality of living with Parkinson's Disease and learning to cope and live well as the disease progresses. Delivered in a matter-of-fact but hopeful way, the offerings suit the teachers, engineers, nurses and other problem-solvers among us. Still a little sketchy in production quality but getting better all the time.
- **The Davis Phinney Foundation for Parkinson's, Every Victory Counts**, usually puts a positive spin on everything, offering encouragement and helping people see life from a different perspective in a very relaxed atmosphere. They appeal to the "touchy, feely", tender-hearted souls, the Social Workers, social services workers, the helpers, and the ones who would like to be. Production quality is a little less reliable.
 - I loved the Davis Phinney presentation by Dr. Ron Postuma (Canadian), the conversation guided by Dr. Soania Mathur (another Canadian), on Sleep and Parkinson's Disease. Dr. Postuma was speaking in what appeared to be an empty cafeteria, and every so often he would spin around in his chair, scratch his head, readjust his position and just **talk** to Soania as if they were two friends talking. While I am more of a "facts" person as my way of collecting information, I loved that he managed to connect with his audience in such a setting, and I



came away with a warm-hearted feeling that “he cares, my problems aren’t insurmountable, they are not such a big deal, I’ll be able to cope with this”.

- **The Michael J. Fox Foundation** presentations are usually research based but approached from a person with Parkinson's point of view. Somewhat similar to the Davis Phinney approach of conversations as a means of disseminating information, it is great for the “feelings people”, but it drives the “facts people” crazy! Production is getting more reliable all the time. Dr. Dolhun’s little info bites are good but lacking the relational aspect of “I want to feel like someone is talking to me.”
- The presentations from the **Parkinson Foundation** are most similar to the ones of Parkinson Canada. Very fact based, encouraging and offering hope based on the progress of research. They offer a variety of subjects from scientific data to everyday living to communication. They tend to appeal to the “just the facts, ma’am, just the facts” sort of people who want to arrive at their own conclusions and calculate how to apply the information to their own life. They seem to appeal to a fairly broad audience because their numbers in attendance have been going up exponentially. When I first started attending it was exciting if there were 150 on a webinar, the last one I attended was about 1350 if I remember correctly. Production quality is usually very good. They have always been the easiest to recommend because they could be “counted on.” Counted on to give excellent information in a meaningful and useable way, as well as delivery without glitches.
- I hope that helps you in your decisions as to which one to watch or participate in! If you would like to add any comments to this rough assessment, please send them to me anytime.

Exercise Break – Thanks, Lillian, we were ready for that!



DOLLARS & CENTS, NEWS & VIEWS

Parkinson Canada has spoken to our group’s leadership team and conveyed to us the following message about “our” bank account:

Excerpt from Amanda Stanton's letter:

"We have changed the way we manage local banking and tax receipting to adhere to CRA guidelines. There are no other immediate changes to expect. All funds in the account will be used in Sudbury to fund the ongoing commitments, activities and programs that the group is accustomed to.

Your CEC will remain your contact for the support group and she is there to provide you with the guidance, tools and resources to manage the support group. Parkinson Canada is working towards equitable access to programs and services across Canada, and looks forward to working with leaders and groups such as yours so we can receive feedback on how we can best serve the needs in your community.

Don't panic, the Support Group will be carrying on and Parkinson Canada will continue to support the group through that lens. For example, if the bank account balance was \$ 0 tomorrow, we would still support the group with what's needed to facilitate the support group: a meeting space, resources, etc. I know you go above and beyond and have a lot of extra offerings, but those are all pieces we can discuss when we get to that point. The group members should not expect to feel any of these changes nor expect a gap in service."

Our support group activities such as monthly meetings, guest speakers, events, etc. will all continue. The exercise classes that we fund will continue until the funds in our “account” run out. The monthly newsletter/meeting notes will continue also until the funds we have accumulated run out. Then the effectiveness of these programs will have to be evaluated and a decision made as to “what next”. We will not be able to add to our Parkinson Canada account. Memorial donations and other donated funds requiring tax receipts will go to the work of Parkinson Canada. This will include the research they fund and improve their ability to provide the educational materials we use and the services offered to various communities.

In effect, what they have told us is that the funds accumulated to date, while they are still ours will be spent in collaboration with Parkinson Canada (Amanda Stanton will be our connection there). This will allow Parkinson Canada to be sure that funds receipted through their charitable number are spent in a CRA-approved manner. Unfortunately, funds already accumulated by the group that were raised in a way that did not generate a tax receipt, such as games & draws, cakes & cookies, coin boxes, cannot be separated out. All bills for expenses we incur need to be charged to or submitted to Parkinson Canada for payment. No more running around to get cheques signed to pay our bills!

Plan going forward:

Your Sudbury Support Group leadership team is setting up a bank account at the Credit Union that will be used to accumulate non-receipted donations and money from our local support group fundraising activities. This money will not be touched until the funds in our account, now controlled by Parkinson Canada, are used up. If at all possible we want to be able to continue to provide the quality of caring and programming that we currently have. Please email any questions to noralearcand@gmail.com. We will pull together the answers for you.

Questions to be answered:



- Can we still earn money or fundraise for the Support Group? Yes, as long as it is non-receipted.
- What expenses do we currently have that might not meet CRA approval?
- What is the spark that brought about this change?
- One comment on the statement “how we can best serve the needs in your community” was to “leave well enough alone.”
- When we use up our accumulated funds, will Parkinson Canada still underwrite our exercise program?

We postponed **LEARNING THE PARKINSON LINGO**, to another meeting. Those of us who have had Parkinson’s for a while and who have done a lot of reading on the subject find ourselves using weird words and medical jargon without thinking. PD seems to have a language of its own.

When someone is newly diagnosed and wanting to learn about Parkinson’s, the words we use can be somewhat baffling. Perhaps it is our spouse who needs some clarification. Or maybe its words we hear our doctors use and we’d like to know what they are really saying. We’ll help each other define those words.

Next Meeting:

June 16, 2021 at 2 pm

We look forward to seeing you then.

Enjoy the warm weather