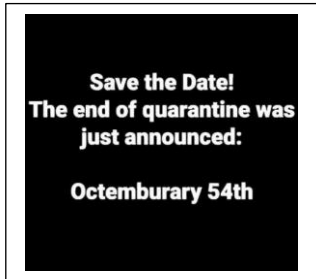


**Welcome** – President Wayne joined the melee as people logged on and he welcomed everyone to our first meeting of 2021. We started with a couple of Covid jokes, setting a lighthearted tone for the afternoon. The jokes will be interspersed throughout these notes in no particular order (my memory may be good, but it's not that good!). It was such a beautiful sunny day, we didn't mind the crispness of the air (-10C) as we didn't have to go out in it. There are some advantages to meeting online!



My husband purchased a world map and then gave me a dart and said, "Throw this and wherever it lands - that's where I'm taking you when this pandemic ends." Turns out, we're spending two weeks behind the fridge.

Does anyone know if we can take showers yet or should we just keep washing our hands?

**Christmas Cake & Cookie Profits:** Claire reported on the Christmas Cake & cookie profits: we are just shy of \$3000 in profits. In light of the Covid protocols limiting our normal sales venues, this is totally amazing! Thanks and congratulations to our Sales team, Chris & Claire, Brian, Raymond & Myrna.:

Quick question: Have any of you heard any complaints about the Christmas Cakes being too sweet? One person registered a complaint with Parkinson Canada and he contacted me by phone – he loves the tins, but the cakes are too sweet, especially for diabetics. He has another idea for a fundraiser that is not so sweet, I believe it was from the Fromagerie, a cheese & cracker basket of some sort. Any thoughts?

Wayne shared some exciting news: For some time now we have realized that we needed to do some succession planning, to allow for the smooth continuance of the support group should he and I not be able to carry on with our current commitments. Louise & Richard & Brian stepped into the gap when Nora Lea had her DBS surgery and subsequent complications in 2019, and they have now agreed to join our newly-forming leadership team. Wayne will continue on as President, Nora Lea as Secretary, Claire Sheridan as treasurer. Just so you know who you have working for you, here is a little information on each of the team:

**Claire Sheridan** has extensive experience in the volunteer sector, working with the Kinettes, the UCT/ACT group, and helping create the House of Kin. She and her husband Chris, who has Parkinson's, head up our Christmas Cakes & Cookies fundraiser. Claire has been the support group treasurer for the past 6 years.

**Nora Lea** brings us her nursing experience and prior secretarial background along with 30-some years of living with Parkinson's. Helping people learn to live well with Parkinson's Disease has become her passion. She is the mother of two grown up children and the grandmother of one little red-headed girl, about whom she writes stories. Nora Lea has been secretary forever, sliding into the role some time after starting as write and editor of "The Parkie Pal" in 2003.

**Wayne** comes to us with a 50-year background in mine ventilation design, as well as experience as a farmer, a Toastmaster, and a leader at All Nations Church. He had practised retiring a number of times before he got it to stick. He has been married to Nora Lea for 40 years and has been learning about Parkinson's from the ground up." Wayne has been president of the Support Group for almost 8 years.

**Brian Matthews** has spent over 30 years in an IT (Information Technology) career. Backed with a Geography degree rather than a traditional Computer Science degree, he focussed not on the technology itself, but on what business

opportunities technologies can open across a wide range of business sectors from banking to mining. Diagnosed with PD almost 7 years ago, and now retired, he has been focussing on finding, exploiting, and sharing these same opportunities in his fight against PD. One of these is Rock Steady Boxing. He is one of the original members of the boxing group, and misses the sessions during the COVID lockdowns.

**Louise Picard** brings to the table a hearty appetite and a wealth of good French Canadian cuisine. She also has a background in public health including public health nursing, genetic counselling and experience in education, research and evaluation. With 16 years of living with Parkinson's, Louise has learned how being connected is key to living well with PD. She feels very fortunate to have a circle of support from Richard and family, including her 6 grandchildren, and of course from her friends and her Parkinson family. She welcomes the opportunity to contribute to our Support Group.

**Richard Carriere's** experience in Social Work education and his community development work combine well with his enjoyment of meeting new people, his sense of humour and his success in helping to raise funds for the Parkinson Superwalk, a cause that he is passionate about. This initiative is critical to help fund the necessary research to find a cure for Parkinson's Disease. Richard & Louise celebrated their 50<sup>th</sup> anniversary this past summer, in a Covid-acceptable manner. (Applause from the group at this.)

### Other Announcements

**Richard** has agreed to head up our Superwalk and he spoke a little about what to expect. It seems likely that the Covid pandemic restrictions will still limit large crowd gatherings and the Superwalk will probably be very similar to 2020, where we walk in family units or with our own personal bubble. Wayne talked about how we handled ours, Garry & Cindy told how they did theirs and raised over \$1000. Richard issued Bruce a challenge to get started on his fundraising soon because he'd be in for some stiff competition this year!

### Parkinson Canada **Parkinson Advisory Council** is looking for members:

In this new and innovative position, the Parkinson Advisory Council (PAC) Member will play a critical role in shaping the strategy and programs that address the unmet needs of patients and families affected by Parkinson's. An "expert by experience", the PAC Member drives patient engagement across Parkinson Canada and provides insight and advice to key decision makers. [Click here for full details](#). This is a volunteer position. Deadline to apply is Jan. 25, 2021.

**Report from World Parkinson Congress partner – Parkinson Connect in UK** – Richard & Louise recently attended a webinar from a partner of the Congress. They were both quite excited by the plan of care coming out of the UK.

**Louise** reported on this new approach to getting personalized resources to a person newly diagnosed. This new model will see a referral from the diagnosing clinician and the patient will receive information specific to themselves, taking into consideration age, ethnicity, locale (rural, urban) etc. Home visits are offered. Here is the link to [more information](#).

We brought a box of After Eights to share with you. This is a very special treat. They are not allowed in Quebec ... where you can't take them out after eight! 😊

. . . Ran out of toilet paper and started using lettuce leaves. Today was just the tip of the iceberg, tomorrow remains to be seen. 😊

**CBC As It Happens** – the story of the magic pill bottle for people with Parkinson's and how Tik-Tok played a part in getting a prototype made in a matter of just a few days: <https://www.cbc.ca/1.5868848> + (This must be interesting, 4 people sent it to me!)

## Other “Show and Tell” items:

Someone asked about walking poles and about whether or not people used them. A number of people commented from their own experience about using poles for walking, snowshoeing, etc. Louise & Richard talked about a collapsible and easily carried pole, Garry & Cindy also recommended the lightweight fold up cane or pole for travel. Garry showed his “stand-up walker” specifically for tall people that helps his posture while giving him the assurance he needs. They obtained it through the North East LHIN, and the occupational therapist there. A percentage of the cost was covered by the government and their insurance kicked in for the rest. [click here](#) for more information about the Dolomite Alpha Advanced rolator. It’s pretty cool!

## Upcoming Events:

**Night Fight with Parkinson’s:** [Acting Out Dreams, Insomnia and Other Sleep Issues](#), a panel hosted by Michael J Fox Foundation, Thursday, January 21, 2021 from 12:00 – 1 PM EST [click here for more info](#) This will be recorded and available on their website under “Third Thursday Webinars.”

**Tuesday, January 26 at 7 pm** [Motivation and Impulse Control, Apathy & Impulsivity](#), a Parkinson Canada Webinar, [find info here](#) This looks to be excellent and will build on what we are discussing today, from an expert’s perspective as well as a person with Parkinson’s. The speaker is a neuropsychiatrist from the Movement Disorder Clinic at Toronto Western/University Health Network.

**Victory Summit for the Newly Diagnosed:** Saturday Feb. 20, 2021 [click to register](#) Join the Davis Phinney Foundation for the first virtual event of 2021 focused on information for those newly diagnosed with Parkinson’s. During this event, you will hear from and interact with movement disorder specialists, neuropsychologists, physical therapists, and people living with Parkinson’s about how to not only understand more about Parkinson’s but about how to [live well and thrive](#) with it. View the [event agenda](#) to learn more about sessions and speakers.

A brand new newsletter to be published seasonally, [here is the](#) [Movement Disorder Clinic Connections](#) Winter edition. You’ll need a cup of tea and a few minutes to skim through the 25 pages and find the ones that interest you. but it is an excellent beginning! If you would like to subscribe to it, please do that yourself.

Appropriate analogy. “The curve is flattening so we can start lifting restrictions now” is like saying “The parachute has slowed our rate of descent, so we can take it off now.” 😊

After years of wanting to thoroughly clean my house but lacking the time, this week I discovered that wasn’t the reason. 😊

**Exercise Break** – Lillian led our exercise break with a game of “Simon Says”. Some of us did better than others at following instructions!

\* \* \* \* \*

**Keynote Topic:** Nora Lea introduced the topic of [“Apathy & Impulsivity”](#) by reading part of this paper:

New Study: Can People with Parkinson’s Experience Apathy and an Impulse Control Disorder at the Same Time?

Historically described as being on opposite ends of the spectrum, [apathy](#) affects about 40% of people with Parkinson’s disease (PD), while [impulse control disorders \(ICDs\)](#) affect between 14% and 40% of people with PD.

How are they different?

**Apathy** — which comes from the French, *apathie*, meaning “passionless existence” — is the feeling of being emotionally flat, lacking enthusiasm or interest in doing anything. Apathy can express itself in different ways, often leading people who experience it to stop

exercising, keeping up with friends and family or even stop taking medications. Of note, apathy is often confused with depression, but they are not the same: with [depression](#), there's a profound sense of feelings of guilt and worthlessness.

**Impulse Control Disorders** (ICDs) are the inability to stop doing something that is harmful, or could become harmful, to yourself or others to the point that they impair one's ability to function at work, home and navigate day-to-day life. Performing the activity can lead to a feeling of elation. Examples include online gambling, compulsive shopping and hypersexuality.

Since apathy and ICDs elicit opposite feelings, is it possible for a person with PD to experience both at the same time? It seems counterintuitive, but may not be. A study recently published in the journal, *Neurology*, "Co-occurrence of apathy and impulse control disorders in Parkinson's disease" (Scott et al., 2020) sought to explore whether a lack of motivation or interest can co-exist with an irresistible urge to perform activities.

WORKING PARKINSON CONNECTIONS

## CONQUERING APATHY

Apathy is not just the lack of motivation. Apathy doesn't just occur out of hopelessness.

Apathy is defined as the reduction in goal-oriented behavior as a result of lessened interest and lessened emotional response.

I feel we are seeing more and more of this especially during these trying times.

Those with Parkinson's disease are more susceptible to developing apathy. Once someone has apathy, they are less likely to feel motivated in doing anything, especially things that are known to help improve symptoms or delay progression like exercise or being socially engaged. Prolonged apathy can be a harbinger of further executive dysfunction and cognitive decline.

This can be terribly frustrating to a loved one or a care partner who recognizes the apathy but feels powerless to help. The article went on to describe a few things that we can do to help overcome this issue and not derail a patient. Both articles are attached.

We were honoured to have [a past-president of the Sudbury Support Group as our guest speaker](#). Dave Rackham joined us from Calgary, to talk about his experience with these issues and to alert people to the possible dangers associated with some drugs prescribed for Parkinson's.

1. **Dave's Story:** [https://youtu.be/321DFcOX\\_cw](https://youtu.be/321DFcOX_cw)
2. **Dave's Update:** <https://www.youtube.com/watch?v=rAkYPnY8n-U&t=7s>

Always a storyteller, Dave had our rapt attention as he spoke and the empathy in the room was palpable. The magnitude of destruction caused by the side-effect of a drug that was supposed to help his Parkinson's, was heart-breaking. The group appreciated his story and they expressed their admiration of his courage in sharing it. There were a number of questions and conversations as we discussed the risk of an impulse control disorder due to dopamine agonist medication. Other stories emerged to confirm this.

As people with Parkinson's, we need to be careful and have someone watching out for us when or if we start taking a dopamine agonist like Mirapex or Requip, particularly as apathy can co-exist and the PWP is unlikely to do anything about it unless it is brought to our attention. (See Jim's story on the article "Apathy – Conquering"). This is a case of "Forewarned is Forearmed".

Reminders: [Parkinson Mobility Program](#) is our exercise program through the Parkside Without Walls and continues Mondays, Tuesdays and Thursdays from 1 to 2 pm, via Zoom. To Register please call Peter Marshall at 705-673-6227 or email him at [Peter.Marshall@greatersudbury.ca](mailto:Peter.Marshall@greatersudbury.ca) and you will receive the link to these sessions.

**The next monthly support group meeting is Wednesday, February 17<sup>th</sup>, 2 – 3:30 pm.**

Nora Lea Arcand, Secretary  
705-522-3321 – cell 705-918-3323