

Meeting Notes **Parkinson Support Group of Sudbury** Jan. 19, 2022

Louise Picard and Richard Carriere (L&R) were the hosts for this meeting hoping to give Nora Lea and Wayne an opportunity to sit back, relax and simply be participants. Nonetheless they are always there behind the scenes when you need them. Louise & Richard thanked Nora Lea & Wayne for their help and for their ever-present support.

The meeting was virtual using Zoom.

R & L welcomed everyone including a new couple from North Bay (by telephone) and another from Elliot Lake. Along with our gals from Timmins, Blind River, Manitoulin Island, we are getting to cover a wide territory!

We thought we would divide the Meeting Notes into three sections.:

- A. Announcements and Report of Support Group Activities
- B. Discussion on today's theme: **Searching for information: "Where to go for Reliable, Helpful Information", a few tips"**
- C. Upcoming events

A) ANNOUNCEMENTS & ACTIVITIES

Some Sad News: We extend our sympathies to the families of the Support Group members and friends who passed away this month.

- Amy St John, Jan. 10th, 2022
- Gordon Sutcliffe, Jan. 13, 2022
- Chris Slack, Jan. 12, 2022



Cake and Cookie Sales:

Fundraising Report. We are pleased to report that we raised an impressive **\$4,035.50** with our cake and cookie sales. On behalf of the Support Group we would like to thank the team leaders, Claire & Chris Sheridan and Brian Matthews. Congratulations and thank you for all the hard work and thanks to all the members who participated in the sales and made this project so successful! Reminder that there are still a few cakes left if anyone is interested. Valentine's Day is coming . . .

Parkinson's Mobility Program

At the time of the meeting, only virtual sessions were available on Monday and Thursday's. However, please note that as of January 31st, sessions are held both on site (in person) at the Parkside Centre and virtually through Zoom on Mondays at 11:00 and Thursdays at 1:00. *Please refer to emails sent to you with more details.*

Volunteers Needed!

There are two research projects recruiting for volunteers. Participating, in research is a way for us to support research and new developments with possible benefit to all of us.

1. **Call from Parkinson Canada** for volunteers to help improve the accessibility of their website.
 - Review and provide feedback on the parkinson.ca website
 - Need one or two people with Parkinson's and also one of the following: seizures, vision impairment, cognitive disability, ADHD, blind or with keyboard navigation challenges.
 - Contact: alison.li@parkinson.ca

2. **Call from Dalhousie University and Nova Scotia Health Authority** to study Managing Fatigue in Parkinson's Disease. See diagram below for information on the study and contact info.

Managing Fatigue in Parkinson's Disease

- Are you living with Parkinson's Disease?
- Do you live in Canada?
- Do you have a device and access to the internet?
- Would you be available to participate in six therapy sessions, three measurements visits and/or one interview session?

If you answer is "Yes" to all questions above, contact us at neda.alizadeh@dal.ca or call (902)222-0744 for more information.

REB file #1027048

6-week Managing Fatigue Course

B) GROUP DISCUSSION

SEARCHING FOR INFO - What are your favourite sites to get good info about Parkinson's?

Well ,honestly , we all know where our favourite source of info can be found - we usually call Nora Lea and she either knows the answer or knows where to look. Hopefully we will learn from Nora Lea and each other today and learn about reliable sites we might want to use. Richard and I thought to get things going we might share two of our favourites and invite you to share what you have found useful. Any tips on where but also how we get info are useful.

1) As a preamble, we want to first mention our own national website which is Parkinson Canada.(www.parkinson.ca)

This is, of course, a good place to start. The info on their site is current, clearly presented and pertinent to us in Canada. A good example is the fact sheet on Dressing

and Parkinson which is a new resource that was presented at a previous meeting. This one page fact sheet is concise and useful and pertinent as we face the multiple layers required to keep warm in our northern region. We invite you to have a look. A link to this resource is [here](#).

2) In our discussion the e-Parkinson Post was also mentioned as a useful resource. It is the online publication of Parkinson Canada. Please note their announcement re website: "In early 2022, e-ParkinsonPost will be moving to the Parkinson Canada website. Please make sure to update your bookmarks. You will still receive the e-ParkinsonPost newsletter in your inbox. If you have any questions, we invite you to contact us."

3) And now back to Louise's favourite resource. It is one most of you have used and the picture is a hint.

Yes, it is the Davis Phinney Foundation which has a wealth of excellent resources. Why my favourite? I was fortunate to attend the Victory Summit in Ottawa and met Davis Phinney. It was a moving and inspiring experience for me - listening to someone who expresses what you feel and believe when you could not find the words. Davis Phinney is a remarkable person and a gifted presenter. We would recommend attending (virtual at present) a Victory Summit if you can. The focus of his Foundation is Living Well with PD so it is one of the first sites that you might want to visit for practical information on managing symptoms etc. but not necessarily what you would choose for updates on scientific research.

Guess who is Louise's favorite resource person?



The Davis Phinney Foundation has assorted resources and an impressive range of topics. You can obtain information by going to the main site and then selecting what topic or type of info you want. The site is very easy to navigate: davisphinneyfoundation.org

Victory Summits (at present virtual) Upcoming opportunities listed further along in Meeting Notes under "Upcoming Events".

Webinars - an extensive collection of past sessions is available.

Blog : Ask the Parkinson Experts. Several past sessions available on interesting topics such as sleep, travel, sharing info with our family.

Actual physical resources, manuals and tools

Exciting news! Parkinson Canada has partnered with the Davis Phinney Foundation to publish their latest edition of “**Every Victory Counts** for Canadians affected by Parkinson’s. This Canadian version of the manual Every Victory Counts. It can be ordered now through Parkinson Canada as a physical book and/or a pdf. File. Both are offered free of charge.

Pre-order possible: [click here](#) or call 1-800-565-3000

4) Another site Louise and Richard mentioned is the site of Parkinson’s UK parkinsons.org.uk

They have a wealth of good information on their website. Easy to explore . One example of their resources is a useful Travel Checklist - just check travel on their topics list. Their site is also of particular interest because they are redesigning their Information and Support Services into a new service Parkinsons Connect. This innovative model, designed with people who have PD, looks at the different ways people want access to help and resources. A model to watch.

5) Another site mentioned in the discussion was the well-known **Michael J Fox Foundation for Parkinson’s Research**. Their main focus is research but they also have very useful resources. They sponsor monthly Webinars and have some current practical resources such as “*Parkinson’s Disease and Diet: A Practical Guide* “. This guide can be downloaded and provides a good overview of the various diets out there and what the research tells us as it pertains to Parkinson’s.

A few points and tips coming out of the discussion were:

- a) Feeling “overwhelmed” with all the information was a common experience, especially when first diagnosed. The need for easy to understand and clear information was mentioned.
- b) The importance of reliable information was high-lighted and the following tips were shared:
- c) Try to find sites that meet your needs. Information we want or need changes with the stages we are in. The need for “newly diagnosed “ info is an example.
- d) When searching check to see if you have the right lingo. For example searching for “clothing and Parkinson’s,” the lingo seems to be “adaptive clothing” so might want to include this in a search.
- e) Checking the source of the information is a critical point to make sure we are looking at a reputable site with current, reliable information. Look for unbiased reviews etc.
- f) Try to limit your search to decrease the number of hits. For example, if you are doing a search on clothing, you might want to add Canada to start with Canadian companies.
- g) Keep a lookout for sites that are of interest and pertinent although they may not be exactly what you were looking for at this time but may be useful in the future.

For example, our search for “adaptive clothing” led to several Canadian companies with impressive choices for clothing but also came up with “*Gift Ideas for your loved one with Parkinson’s Disease*”. Blame it in the Christmas season, but this was actually interesting.

Searching the Davis Phinney Foundation site also came up with some very interesting information from a 2019 Conference on “Little Big Things, Showcasing Parkinson innovations - Meaningful solutions for living with Parkinson’s.” The ingenuity of some of the “little things” is impressive but should be approached with caution since development and evaluations are not yet complete.

The link to the recordings of this conference is:

<https://davisphinneyfoundation.org/little-big-things-a-parkinsons-innovation-event/>

C) UPCOMING LEARNING OPPORTUNITIES

1) From Michael J. Fox Foundation Webinar

***Moving with Mood Changes in Aging and Parkinson's:
A Look at Depression and Anxiety*** February 17, 2022

This month they will replay a popular webinar on mood changes. Panelists discuss how and why mood changes, such as depression and anxiety, happen as we age and in Parkinson’s; how you and your loved ones can talk about these symptoms with each other and with your providers; and what treatment options are available.

2) Michael J. Fox Foundation Webinar

Diet, Exercise and Other Strategies for Living Well as You Age
January 20, 2022 *DATE PASSED. AVAILABLE AS PAST WEBINAR

3) Davis Phinney Foundation: Victory Summit

[THE PARKINSON'S YOU DON'T SEE – FEBRUARY 18, 2022](#)

They are centering our first Victory Summit Virtual Event of 2022 around the autonomic symptoms of Parkinson’s. They will take a deep dive into gut health, pain, and autonomic dysfunction and regulation with some of the world’s leading Parkinson’s medical experts. In addition, they will feature short movement breaks that fit the event’s theme and that will show you how to move to manage these symptoms.

3) Davis Phinney Foundation: Victory Summit - April 2nd, 2022.

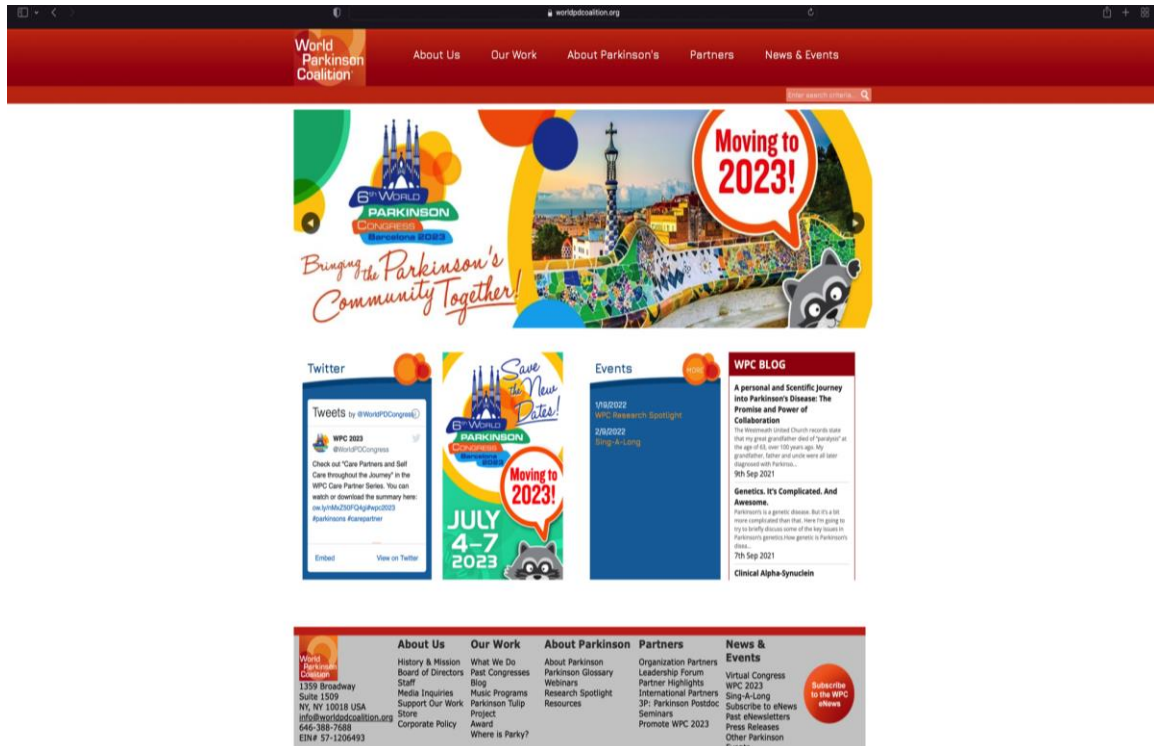
Our Voices, Our Stories. For People with Parkinson’s, by People with Parkinson’s

Sometimes, what you need more than anything is to be seen and heard by others who are traveling along a similar path. That’s what this event is all about. We’re turning over the stage to people with Parkinson’s for an event by people with Parkinson’s, for people with Parkinson’s. Our presenters will show you that it is possible to live well with Parkinson’s today—and to tell you how they do that day in and day out.

<https://davisphinneyfoundation.org/events/#1642083450523-c7adc08a-e59f>

5) World Parkinson Congress July 4-7, 2023 Barcelona, Spain

Those of us who have had the opportunity to attend an international congress would encourage you to consider attending. It is an unforgettable experience. With 3 to 5000 attending, a mixture of people with Parkinson's, their caregivers, physicians, general neurologists, movement disorder specialists, and research scientists; plus other stakeholders in caring for PWP's, such as physiotherapists, kinesiologists, speech/language pathologists and even Parkinson's foundations. It is encouraging to know there are so many people involved in helping us live well despite our symptoms for as long as possible.



Getting to Barcelona is a challenge but if you are interested there is financial help you can apply for from the congress. Check out the site for more info. <https://wpc2023.org/>

Louise and Richard thanked everyone for joining our monthly meeting and reminded everyone of the next meeting.

Next Meeting: February 16th, 2022 - 2 pm via Zoom

The number to call if you don't have internet and want to join the conversation by phone is **1-855-703-8985**.

Our closing thought for today:

Remember that knowledge is power. Better understanding helps us to live well in the present and helps us shape our future.