LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Spring 2015

Parkinson Society Central & Northern Ontario
Société Parkinson du Centre et du Nord de l'Ontario
In Partnership with Parkinson Society Canada

I love that each April, with spring in the air and regeneration all around us, we get an opportunity to reinforce our messages and ensure that as many as possible know of our mission during Parkinson's Awareness Month. Whether it be through visits with MPPs, information tables at health fairs, education sessions, mayoral proclamations, support group gatherings, or through a connection at a tulip sale—we are there to represent people living with Parkinson's in Ontario.

I invite you to get involved in our efforts and help us bring awareness to Parkinson's disease. This issue of LiveWire will fill you in on initiatives specific to Parkinson's Awareness month (such as tulip sales, MPP visits, and cut-a-thon) as well as some ongoing events (such as Sandie's lunch-time presentations) and some activities down the road so you can save the date (such as education events and SuperWalk).

Please continue to send us your feedback as we value your opinion. Thank you to those who participated in our 2014 client survey where we learned about the kinds of information you want to receive in LiveWire and in response, have moved to a 16 page issue to fit it all in! To learn about how you can be part of our 2015 survey take a look at page 13.

Thank you for your support; we would be lost without it. Enjoy this issue of LiveWire. I hope you find it helpful and informative!

Debbie

What We Do

Support Services

We provide consistent and excellent support to people living with Parkinson's and their families to make their lives better. We also provide support to facilitators and participants of more than 50 support groups and chapters throughout the region.

Education

Our goal is to provide excellent seminars and conferences to different areas in the region and online so that this information is readily available. We also offer smaller sessions during support group meetings all over the region.

Advocacy

Our Ontario-wide Advocacy Committee works to influence the behaviour of key government officials and agencies in support of people living with Parkinson's, and build strong relationships with the Local Health Integration Networks across Ontario.

Research

Parkinson Society Central & Northern Ontario fully supports the National Research program and sends all research donations to support this program.

PSCNO could not fulfill its mission without the generosity of its donors and volunteers! To help ease the burden and find a cure, call 800-565-3000 ext. 3378 or visit www.parkinsoncno.ca to make a one-time or monthly donation. ***Thank you for your continued support!***

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Ask the Doctor

Is Parkinson's disease inherited?

In a small percentage of cases, there is a family history of Parkinson's. That doesn't mean that if your parent had Parkinson's you will have Parkinson's but you are at an increased risk. We know that in the majority of people with "inherited" Parkinson's (still the minority), the having the genetic mutation doesn't necessarily mean that you will have symptoms of Parkinson's. It is thought that in addition to having the gene, there are other factors like possibly environment or lifestyles that may also have to be present for symptoms to manifest. At this time, there have not been any environmental factors aside from significant exposure to Manganese (like may occur in miners), that result in increasing the risk of Parkinson's.

Do newly diagnosed patients need to start medication right away?

Pharmacologic treatment for Parkinson's disease at this time is purely symptomatic. That means none of the drugs available are able to slow down, halt or reverse the disease. The decision to start medication is based on whether symptoms are interfering in your life; if they are it is prudent to start and if they aren't, its ok to wait. However, it is important for people to know that "holding out" for the time when you really need it and suffering now is a myth. The only thing that happens by not taking medications early on if you are suffering with symptoms, is suffering. It doesn't mean the medications will work batter later. Many people and even doctors are under this misconception and many studies have now proven that wrong. Even if someone with PD does not start medications immediately, the one aspect of treatment that may be able to affect disease progression is vigorous exercise. Exercise preserves mobility, as well as mental health and cognition as increasingly demonstrated in research. There is no downside to exercising and is now accepted as an important part of treating Parkinson's disease.

What time should I take my medication? My pill bottle says 4 times a day?

What time to take medications is a very important question and no two people are alike. It depends on many factors including when you wake up, when you eat, what time do your symptoms bother you most and do you have symptoms at night that interfere in sleep. It also depend s on which medication you are taking. It is essential that your doctor directs you as to the exact timing of medication for you. In general l-dopa, the most common medication, ay also be the most difficult to prescribe as its effect may change as time passes. Therefore it needs to be modified depending on how you are feeling. L-dopa gets metabolized in four hours therefore, pills should in general not be taking at intervals longer than 4-5 hours; however, in some cases the pills wear off before that time and the doctor needs to adjust accordingly or consider other adjunct medications. If you are having symptoms during the night like tremor interfering in sleep a bedtime dose or one in the middle of the night is advisable; however, if your symptoms are only mostly in the day, a dose before bed is wasted as you are going to sleep anyways. Talk to your doctor regarding the schedule that is best suited for you.

How much levodopa is too much?

There is no "upper limit" of l-dopa. Every person is different in terms of the effect l-dopa has on them. The only upper limit is side-effects. If these occur it is prudent not to increase the dose; however, if there are no side-effects, careful increase in dose is possible. Your doctor should decide this based on careful evaluation.

What symptoms of Parkinson's are most responsive to levodopa?

Again, these may differ for different people and at different stages of the disease. Often very early on, all symptoms may resolve, a period of time known as the "honeymoon period". Over time some symptoms may respond variably compared to others.

Galit Kleiner-Fisman is a Movement Disorders Specialist who is the Medical Director of the Jeff and Diane Ross Movement Disorders Clinic at Baycrest Hospital and an Assistant Professor of Medicine in the Division of Neurology at the University of Toronto. She has developed a multi-media patient website www.livewellwithparkinsons.com and is involved in numerous research projects related to movement disorders in geriatrics.

Research News

Funding Philosophy (Our Niche)

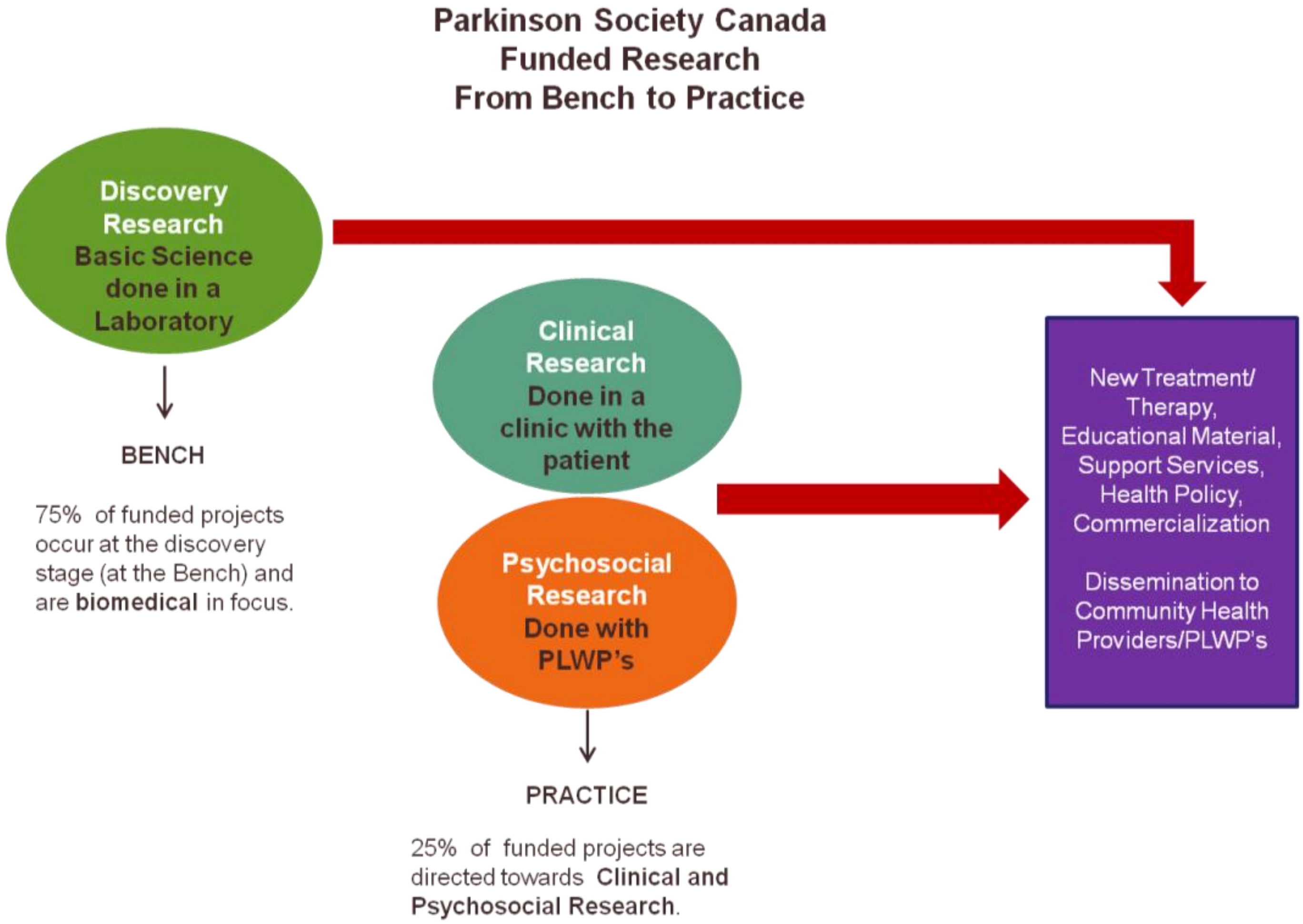
Invest in Canadian Parkinson's research

- **Building capacity to ensure the future of PD research**
- **Supporting novel ideas**
- **Growing number of specialists to ensure high quality of care for people with Parkinson's**

What kind of research do we fund?

- **Investigator Driven**
- **Discovery/exploratory**
- **Psychosocial/Quality of Life**
- **Clinical Fellowships**

Where does our funded research fit in the pipeline?



Parkinson Society Canada
Funded Research
From Bench to Practice

Discovery Research Basic Science done in a Laboratory

BENCH

75% of funded projects occur at the discovery stage (at the Bench) and are **biomedical** in focus.

Clinical Research Done in a clinic with the patient

Psychosocial Research Done with PLWP's

PRACTICE

25% of funded projects are directed towards **Clinical and Psychosocial Research**.

New Treatment/ Therapy, Educational Material, Support Services, Health Policy, Commercialization

Dissemination to Community Health Providers/PLWP's

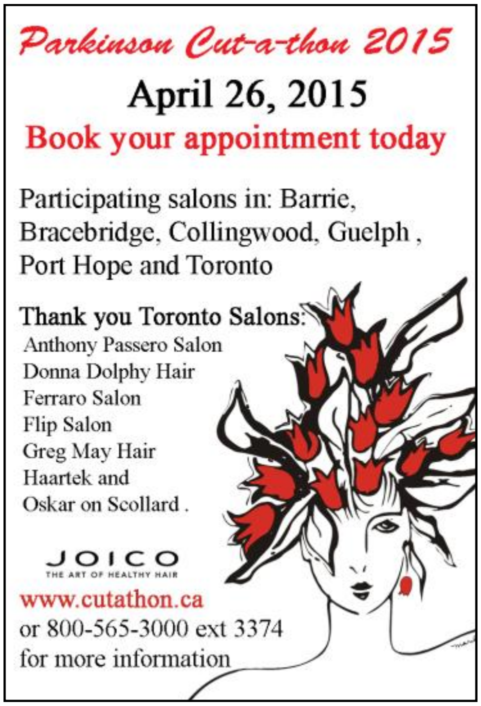
Parkinson’s Awareness Month: Help Spread Awareness During April

April is Parkinson’s Awareness Month, and Parkinson Society Central & Northern Ontario (PSCNO) will be dedicating their efforts to spreading awareness and raising funds for people affected by Parkinson’s. The entire month of April will provide many opportunities for supporting our mission to provide advocacy, education, research and support services to those affected by Parkinson’s. This year will mark the 50th anniversary of Parkinson Society Canada and we intend to show the community how much has been accomplished in 50 years.

April will be kicked off with our 31st annual Hope in Bloom campaign to sell tulips to raise awareness and funds for Parkinson’s. The tulip is a symbol of hope for people living with Parkinson’s disease. Tulip volunteers will be seen throughout Ontario selling tulips during the month of April - $10 for fresh cut bouquets or potted tulips. You could also become a Tulip Ambassador and sell tulips at your own organization. If either option interests you, please contact Helen Wong at 1-800-565-3000 ext. 3377. With winter on its way out, there is no better way to welcome spring than with tulips.

Also during April there will be the Cut-A-Thon which provides participants with a wash, cut and style for a set donation that contributes towards Parkinson’s. This year’s sponsor (Joico) will be providing free gifts to participants. The event will be taking place April 26th in multiple salons throughout Barrie, Collingwood, Guelph, Port Hope and Toronto. Visit www.cutathon.ca to find a list of participating salons. All the stylists donate their time and every penny goes towards Parkinson’s.

Every year, we plan events in the month of April recognize people with Parkinson’s, and the support groups we have established throughout central and northern Ontario. The recent National Population Health Study of Neurological Conditions predicts that the number of people with Parkinson’s will double by 2031, and the reality is that Parkinson’s needs more recognition, more funds for research, and more support for those affected by it. PSCNO will be hosting an advocacy day at Queen’s Park on April 15, where Parkinson Ambassadors will be visiting with MPP’s to discuss Parkinson’s issues. In addition, Community Developer Coordinators will be conducting April awareness initiatives at the community level, and encouraging cities and towns to proclaim April as Parkinson’s Awareness Month. Parkinson’s is a growing in Ontario; join us this April to help us spread awareness and highlight the needs and accomplishments of those with Parkinson’s and their families.



Parkinson Cut-a-thon 2015

April 26, 2015

Book your appointment today

Participating salons in: Barrie, Bracebridge, Collingwood, Guelph , Port Hope and Toronto

Thank you Toronto Salons:
Anthony Passero Salon
Donna Dolphy Hair
Ferraro Salon
Flip Salon
Greg May Hair
Haartek and
Oskar on Scollard .

JOICO
THE ART OF HEALTHY HAIR

www.cutathon.ca
or 800-565-3000 ext 3374
for more information

Become a member of the James Parkinson Heritage Circle

Gift planning, simply put, is the act of planning a gift to Parkinson Society Central & Northern Ontario. Here are ways to make a difference through a bequest in your will or a gift of life insurance policy:

- invest in PSCNO’s greatest need
- contribute to a specific programme
- donate to research and help find a cure
- commemorate a life

All of the above are ways of making sure your gift of support today and hope for tomorrow is easy. For more information, contact Naseem Jamal at 416-227-3378/800-565-3000 ext. 3378 or naseem.jamal@parkinson.ca

The Nurse’s Desk

A Painless Discussion

Sandie Jones, RN

By the time you read this article, I will be celebrating the beginning of my 17th year working with Parkinson Society Central & Northern Ontario. Many changes have taken place during my tenure here including changes to the name of our organization, the number of staff, and the number of support groups. Our support group network is over 50 groups across our vast region. When I started there were just three staff, and now there are fifteen of us!

Just as there have been changes and progress here, so too has there been a great deal of progression in the understanding of Parkinson’s disease (PD). Not that long ago, PD was regarded as a painless condition, but I know many of you would dispute that!

Many of you are only too aware of the fact that other than problems with movement (tremor, slowness and stiffness) there may be non-motor symptoms that have an ever greater impact on your quality of life. Pain is one such non-motor symptom that has garnered some attention in recent years by researchers and health care professionals. Although there are still a lot of unanswered questions about pain, I will share with you what we do know.

The scientific literature varies greatly regarding the prevalence of pain but somewhere between 33% and 85% of people living with PD report pain as a troubling symptom. That’s a lot of people! Pain is also not a normal part of aging, but the belief that it is normal is one reason many people suffer needlessly.

People living with PD can experience many different types of pain, but there are three main causes I will focus on today: progression related; wearing-off related; and non-PD related pain.

Progression related

As PD progresses, the muscles become more rigid which may produce a deep, nagging pain. This type of pain usually relieved with an adjustment in medication. If muscle stiffness was one of your initial symptoms, this symptom may be familiar to you, as is the benefit from medication. Talk to your specialist.

Wearing-off related

Increase in muscle tone – overactive muscles – or partial contraction of the muscles that result in spasms or dystonia cause a different sort of pain. These muscle contractions are involuntary, meaning they are not under your control. Most often these spasms affect the feet and toes, fingers, neck and back. Often these spasms occur as medications are wearing off, particularly in the early morning. The most common solution is to ensure that the level of medication does not become low enough to allow spasms to occur. Sometimes, taking a time-release medication at bedtime or a dose of medication during the night can help with this, so again, it is important to talk to your specialist.

When someone is in an ‘off’ state (when medication wears off before the next dose is due) or when PD is inadequately treated, pain from any source seems to be magnified. If a person has fluctuations during the day (when meds work well and when they don’t), the degree of pain fluctuates too. Therefore, when motor symptoms – tremor, stiffness, slowness – are well controlled, pain due to other causes may be well controlled too.

Non-PD related

Of course, you can also have other conditions, such as arthritis, bursitis, or tendonitis which can also be painful! The treatments for these problems include pain relievers and are different from PD treatment, so it is important for you to partner with your doctor to try and figure out which disorder is causing the difficulty. Sometimes, just to confuse things, the problem is mixed: for example, stooped posture related to PD may impact on sciatica, which is a pinched nerve in the back. One thing is for sure: pain from any other disorder clearly gets worse when your antiparkinson medications wear off.

It is very important to address pain, as it may interfere with your daily activities; your mood; your sleep and your overall quality of life. Chronic pain can result in sleep disturbance, malnutrition, social withdrawal, depression, anxiety and even impair cognition.

In conclusion:

- Pain that is attributed to PD can often be alleviated by starting antiparkinson medications, or adjusting the dosage you are currently on.
- Causes of pain can be tricky, and PD might get blamed for everything you experience. Though PD may worsen pain you have, the cause may be another source.
- Keep a diary of painful symptoms, including time of day and the location in your body affected. Use descriptive words: e.g. sharp, constant, dull, occasional, throbbing etc. This will help the doctor to narrow down the cause, and suggest treatment options.
- Physical therapy and mild exercise, massage therapy and warm baths can be helpful as non-medical approaches.

There are no cut and dried answers about why pain occurs in PD, but research is happening right now. There are already good strategies in place for managing pain so don’t suffer needlessly, and please talk to your doctor!

Perceptions and Problems

Robert TerSteege, CIRS

I've always loved optical illusions, such as the Rubin's vase, where you either see a vase or the silhouettes of two people in profile. Once you see the hidden figure, you wonder how you never saw it in the first place! Challenges in life are like that: sometimes you need to change your perception in order to see things in a new way, but once you do you find yourself wondering "why didn't I think of that before?"

Regardless of PD, your life is a series of challenges to be dealt with, ultimately by you. No one can live your life for you, so it is up to you to try and see the best solution for yourself!

Professionals can tell you can have a good quality of life living with PD, but we don't say everything is going to be easy. We tell people living with PD they have three things to have a good quality of life: medication; exercise; and attitude. Your specialist is going to deal with your medication. We can suggest going to a physiotherapist, fitness classes at your local community centre, or home exercise. We can tell caregivers to prevent burnout to make time for their own selves, and practice good self-care.

Nobody can make you take pills or advice. Nobody but you, that is. Your attitude to the challenges you face is something only you can control. No one in this world knows your own needs or resources in this world better than you.

How you choose to address PD is going to be the same as how you choose to address the other challenges in your life. It's still up to you to do the work. There is still no guarantee that everything will work out perfectly, but being prepared is going to give you every advantage over someone unwilling to try.

It is not easy to try and change your attitude, especially if you are faced with particularly difficult physical symptoms, dealing with depression or anxiety. Here are four suggestions to help get you started.

- Ask yourself "What's in my control?" – If you have no control, what can you adapt? Are there ways to give input?
- Ask yourself, "What stress can I get rid of?" – E.g. if going to the grocery store is stressful, do you have a delivery service?
- Simplify things – E.g. can you auto-pay bills?
- Make room in your life – Physically, mentally and spiritually! Get rid of or gift things you don't need, and make your physical space easier to manage. Mentally, make time to unwind and put stress on hold, even for five minutes a day. Spiritually, whether you are religious or not, make room for the small joys and victories day to day that can make life special.

It takes courage to try and deal with problems in life. It takes time to stare at a problem, until a solution can be seen. If you can't find a solution, don't be afraid to ask someone for input. Someone may have the suggestion that helps change your perception, and give you the power to deal with a problem!

I would invite you as the personal expert living with PD, or as a carepartner to share with your fellow LiveWire readers, what was the best tip that you have to deal with a difficult symptom? Also, what problem are you having in your day to day right now that you can't seem to get an answer for from professionals? Send you tips or questions to livewire.editorial@parkinson.ca. All answers and questions will be printed anonymously, and edited to protect personal information.

Life's challenges will continue every single day, for every single person, living with PD or not. If you are feeling overwhelmed, and think you just can't handle things, I would share this quote from Mary Anne Radmacher: "Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says I'll try again tomorrow."

DBS: Memories and Musings

Lorne Collis underwent Deep Brain Stimulation (DBS) in July 2014. Here are his thoughts and feelings—in his own words.

Thursday July 3, 2014 4:00 a. m. Alarm goes off. Taking reduced dosage of Parkinson meds, as directed, prior to arrival at hospital.

5:50 a. m. Arrive at hospital. Proceed to Pre-Op Clinic Unit (POCU). POCU does not open until 6:00. Directed to waiting room with other early patients.

6:00 a. m. Called into POCU, where receptionist calls my name first. Checks my id, puts wristband on right arm, and directs me to bed number five, my home for the next few hours.

Bed number five is the last bed next to the door of the operating suites. Every are taken through this door. Automatic door opener—squeaky door. World class hospital, let's take up a collection for a can of WD40.

Nurse brings me my surgery clothes. She tells me that aside from my wrist band, if I wasn't born with it, take it off! Lovely hospital gown open in the back. Another one, open in the front. Booties. And a treat. Pyjama pants. One size fits no one.

BP 210/192. Yah, I'm not nervous!

7:10 a.m. Time for my first procedure. I walk, trying to hold up my pants, to Diagnostic Imaging, where they will install the "frame" and do a CT Scan (normally an MRI, but I had already done one three weeks earlier). As Toronto Western is a teaching hospital, we will be introduced to several very young residents who will be taking part in the surgery. We are met in the CT waiting area by a young doctor who we refer to as "the 5 year old." He is the doctor who will ultimately do my surgery (under the supervision of my neurosurgeon.) He proceeds to tell us this may be the worst part of the entire procedure.

We are joined by Dr. Kalia (the neurosurgeon) who is going to install the frame. He takes out four very long needles (Rhonda described this part as getting a Botox injection) and he proceeds to freeze my forehead and the back of my neck.

Using a screwdriver (that's what it looks like), he then screws the frame into my forehead and the back of my neck. The frame is not heavy (some lightweight metal alloy) but is not very comfortable. I joke that I could now play goalie for the Leafs and he advises that when they attach the front guides in the surgical suite, this goalie mask has a value of about $140,000.

They attach a dark Plexiglas insert (which has all sorts of lines and markings—for measuring purposes) to the front, and then walk me to the CT scanner. The ride back to POCU is in a wheelchair; they don't want me walking the halls and bumping into things with my $140,000 goalie mask on.

Hurry up and wait for the operating room to become available. And you can't lie down with this frame on; it has a bar across the back that prevents you from putting your head all the way back.

10:00 a. m. My scheduled surgery time. The surgeon comes in and tells us there will be a short wait of 15 to 20 minutes (turns out to be 45) while they clean the operating room from the last procedure.

We are joined by the anesthesiologist. My saviour. You can say you are ok all you want, but the tremors don't lie. By this point I was bouncing all over the table. Try to put in an IV line in a moving target. Big man, first name was Anil. Worked to calm me down. Asked what my favorite music was and then pulled out his iPhone and found some songs on Youtube to play in the operating room. Kept holding my hand during surgery, monitoring my BP (which had come down to 137/75) and asking if I was okay. A comforting soul in a scary, sterile place.

The surgery portion is a bit of a blur. A whole bunch of memories colliding. In no particular order:

- They start the IV drip to calm you down.

- A few more needles to the head, to freeze the area they are about to work on.
- Lots of people in the room. The surgeon, the 5 year old, the anesthesiologist, several nurses, and several sound technicians (will get to that part soon).
- They put this plastic tent over your head so they can watch you and you can see them.
- Dr says, " we are going to start to drill…you should not feel anything"…..WRONG! A little more freezing solves that problem.
- The drill sounds like a construction drill, you feel the vibration in your head, but no pain.
- They then insert the electrode into the hole.

The next part of the procedure seems to take forever. They are trying to determine the correct depth using sound waves. The electrode is lowered and raised in .1 mm increments, and the "record producers" listen to the brain waves (loud buzzing noises) until they feel they have the right spot. (I have been watching too much Nashville lately, but to me, it was like listening to a record producer tweak the sound.)

The surgeon then holds up his index finger in front of my face and says how many fingers do you see. Because of my double vision without my glasses, I say 2 and he laughs. They move the wires around and he asks if the distance between them is changing. This goes on until he is satisfied they have the right spot.

DBS: Memories and Musings

He then asks me to make some motions with my hands. He is manoeuvring my left hand when the IV comes out. The replacement anaesthesiologist (there are 2 due to the length of the surgery) tries to put it back in, but the tremors have returned. It takes Anil and his soothing character to slow down the tremors and reset the line.

Once they have narrowed down the location, the doctor yells “lead up” and everyone in the room, except me, puts on a lead gown, and an x-ray machine guides them in putting the wires in just the right spot (two monitors in front of me, which mean nothing to me.) The surgeon is pointing out to the 5 year old where the probes are on the screen and directing him on how to proceed.

One side down, one to go. I am told the second side usually is faster.

We go through the same steps again, this time working with my right hand.

When the doctor shouts “lead up”, I ask why everyone in the room is suiting up except me. Draws a good laugh from the doctors.

When the second probe is inserted, I am told they will now clean the wound and sew me up. I ask if I can have some of the good stuff now? The anaesthesiologist says of course, and that is the last thing I remember until I wake up in recovery.

3:00 p. m. Recovery room. Frame is gone, my head is covered in bandages and I have a doozy of a headache. Surgeon comes in and tells me surgery was very successful. They think they got the probes in the right spots.

3:30 p. m. Taken to a private room on the fifth floor.

Friday July 4, 8:00 a. m. I am taken down for an MRI to make sure the electrodes are in the correct location. Pass with flying colours.

10:00 a. m. Scientific experiments: the most disappointing part of the whole week. I was told that I could volunteer to participate is a study between surgeries. Because the wires were hanging out of the top of my head, they could hook me up to a computer and watch my brain activity as I performed certain tasks. This sounded interesting, and I immediately signed up. (There has to be some benefit to brain surgery).

The testing could take up to four hours. Because Rhonda and Lisa were coming to visit round noon, I told them I was good for about 2.5 hours. Not a problem.

They take me in a wheel chair to the lab on the 13th floor (is that an omen). Having participated in a previous study, I should have been prepared. The room is filled with old PC’s sitting on make-shift shelving. They ask me to sit in a chair borrowed from Goodwill.

The electrodes from my head were attached to a mixing panel and the audio waves from my brain were shown on the screen. They then set off an electromagnet near my head and watched the activity on the screen, adjusting the frequency on the monitor so that the reaction looked bigger on the screen.

The first test was as follows: The Letter T or Y would appear in white or red. If it was white, I would identify the letter verbally. If it was red, I would say nothing. The speed of the letters appearing would increase and then they would set off the electromagnet at the same time and measure my responses. The jolt from the magnet was very distracting, and it almost made my teeth hurt. After about 20 minutes I had had enough.

The second experiment involved me resting my chin on a stand and watching circles with an arrow inside. I was supposed to move my index finger in the direction of the arrow, and they videotaped my response. I found myself dozing off and missing arrows. Finally, I got frustrated and said that was enough for one day. While I was disappointed in the process, the researcher was thrilled, as I was the first subject, and they finally had some REAL data to look at.

Back to the room for a nap. Before we left, the doctor running he lab had to tuck the wires back into the bandages. He made me the perfect turban. What is amazing is that, even though the device is not connected my Parkinson symptoms are gone. NO tremors, NO stiffness. It is only after 2 days back on my meds that small signs of dyskinesia reappear.

Saturday July 5 The highlight of the day was lunch. Lisa brought me a smoked meat sandwich from Caplansky’s which I ate at the picnic table outside the hospital.

Monday July 7 Getting ready to go out for lunch. Nurse comes and advises I am being evicted. They need my bed. Being transferred to a semi-private room in another wing.

Tuesday July 8 Second surgery. Scheduled for 10:00 a. m. No breakfast this morning – not missed. Put an IV drip in arm. They wheel me down to POCU. Same surgical nurse as last week. The good news is I will be asleep for this one.

Over the next 20 minutes I am visited by the surgeon, the anaesthesiologist (a different one), and the 5 year old.

Surgery is uneventful. Wake up in recovery about 1 hour later with a bandage on my chest. Surgeon comes in and advises all went well, and I can go home tomorrow. Just want to sleep now!

Wednesday July 9 Early visit from the surgical team, then the surgeon, then the Mobility Nurse Practitioner (who I will be seeing in August for programming). All say I can go home this morning. YAY! My own bed. I am dressed and packed and ready before my “breakfast” arrives.

Wed July 16 Staples removed from my head. Almost as much fun as the surgery. Chest not healed yet. Come back Monday to remove those staples.

Monday July 21 Staples removed from chest. Head is healing nicely. Parkinson symptoms starting to return. PLUS a new one…tremor in right leg.

Tuesday July 22 Dentist appointment. They refuse to do anything without clearance from the surgeon. Concerned about bacteria and infection. Will have to reschedule.

Continued on the next page

Deep Brain Stimulation

DBS: Memories and Musings

Four months later. The following update discusses the "programming" process.

When you leave the hospital, the DBS unit is OFF. You must wait six weeks for the swelling to go down in your brain before they can turn it on.

During the six-week wait, some people experience "The Honeymoon Period." You have NO symptoms. Then, as the swelling goes down and the meds again begin to accumulate in your system, you slowly return to the pre-insertion state. For me, the honeymoon lasted two weeks. Then the tremors started to return. For some reason I did not experience the severe dyskinesia that I had before the surgery—it was there, but milder.

The first programming session was scheduled for August 26, 2014. You have to go to the hospital "off" your meds. I am getting pretty good at travelling into Toronto by GO Train without my morning meds.

I learned there are 4 wires attached to each probe. The programming tests the firing sequence and increased voltage that gives you the best results. During the 2 hour process you watch as the tremors come and go and come back again. They have to "dial it back" to allow for the effects of your medication. If you have zero symptoms, chances are you will experience severe dyskinesia once the meds kick in.

During the process, they watch for side-effects of the stimulation (tingling in the hands and feet, vision issues); anything abnormal is documented next to the programming data in your chart. This way they can refer to it later when re-adjusting.

I was then told to take my morning meds, and have some lunch. If there was no adverse reaction in one hour, go home and come back in one week.

I have discovered there is a very fine line between too much stimulation (dyskinesia) and not enough (tremors). Two months into the programming and we still can't seem to perfect the settings.

The most challenging session was week number two. After taking my meds, I started to develop dyskinesia. Rather than return to the hospital, I figured as my body adapted to the meds, it would subside. WRONG! A visit to the Art Gallery of Ontario (AGO) turned ugly when I could not control my movements. A nap in the cafeteria did nothing to help. It then took me almost 15 minutes to send a one-line text to my son to arrange for transportation home. The next day provided no relief. I finally turned off the unit so I could send an email to the hospital explaining the situation. An appointment was made for the next morning, at which time we changed not only the voltage, but the firing sequence. Not perfect, but I think I would rather have minor tremors than dyskinesia.

I am now on a monthly schedule for re-programming and tweaking. I have gone from 23 pills per day to 10 ½. I was down to nine but one has to be careful not to reduce the Requip too fast, or depression sets in. It was not severe depression, but enough to cause concern, so they slowed the decrease in meds, and actually bumped the dosage to more evenly space the time between doses.

I think when they eventually reduce the meds farther, they should be able to crank the voltage to eliminate the tremors without inducing dyskinesia. But slow and steady for the time being.

The interesting thing about my symptoms was that before the surgery, I did not know how bad the dyskinesia was. Until I saw a video of myself, or my wife complained to the doctor, I thought I was doing just fine. Since the surgery I can FEEL the onset of dyskinesia before anyone else actually sees it. I seem to be able to anticipate when I will have balance or movement issues, and can attempt to minimize the effects on my body.

Am I 100% better? NO, and I probably will never be. I think my expectations may have been a little ambitious. However, I would say I am 75–80% improved. The defining moment came on September 6 at the Mississauga Parkinson SuperWalk. I was not a participant, but the organizers had asked me to address the crowd before the walk. As the walkers started on their way, I went to the DJ table, grabbed my camera, and ran to the next street corner to take some pictures. As I am running, I remember thinking, "What am I doing? I can't run?" At least I couldn't run 2 months earlier!

Join the Partners for Parkinson's monthly giving club. For more information, contact Naseem Jamal at 416-227-3378/800-565-3000 ext. 3378 or naseem.jamal@parkinson.ca

Parkinson's Voice Heard at Provincial Pre-Budget Submission

Recently Parkinson Society Ontario (PSO) had the opportunity to appear before the provincial pre-budget hearing. This time was used to highlight the challenges of those affected by Parkinson's, the costs of the disease to the province and what may be done to mitigate future costs.

With 40,000 people in Ontario alone diagnosed with Parkinson's and more than 160,000 Ontarians affected by the disease, it is quite clear that it is an issue deserving of Ontario's attention.

One of the indicators of the urgency presented by Parkinson's is the recently published Canadian National Population Health Study of Neurological Conditions. This study predicts that new cases of Parkinson's will double by 2031, and the next 20 years will see health care costs for those with Parkinson's and Alzheimer's to be twice as high for Canadians age 40 and older than other neurological conditions studied. With this is mind, PSO offered suggestions how to not only mitigate the costs to our health sector but to also provide the proper health care that people with Parkinson's deserve.

The key issue addressed was the wait times for a neurologist specializing in movement disorders. Research shows that 50% of parties who did not see a neurologist or specialist had higher occurrences of hospitalization. Therefore reducing these wait times can also greatly reduce the impact on the health care system and economy of the province. The following are the suggestions PSO put forward to accomplish this.

- Adopt the McGill Movement Disorders Program; the program specializes in training nurses to care for people with Parkinson's.
- Greater support in the access of video conferencing services such as Ontario Telemedicine Network. Such services help more remote families get access to neurologists.
- Stronger effort on training, retaining and increasing the number of neurologists specializing in movements disorders.

These examples would not cost a great deal of money and could go a long way to improving access to neurologists. We estimate approximately $750,000 would allow Ontario to implement these means of increasing access to proper care for thousands of people with Parkinson's. **That is only $4.69 per person in Ontario affected by the disease.** The savings in avoided ER visits and hospitalizations would pay for this within a few years.

Our presence at the pre-budget hearing would not have been possible without the Parkinson Ambassador program. We are currently looking for motivated individuals to help move Parkinson's issues forward in the 2015 election and beyond. By becoming a Parkinson Ambassador you can be a champion in your community and the voice for Ontarians with Parkinson's!

If you are interested in becoming a Parkinson's Ambassador, please contact Jared Zaifman at Jared.Zaifman@Parkinson.ca.

Online Carepartner Support Group Available

Do you find it impossible to find time to attend a carepartner support group? Would you attend a carepartner support group if there was one in your area? If you answered yes to either of these questions, we have a solution for you.

Parkinson Society Central & Northern Ontario (PSCNO) now has a Psychotherapist, the primary Carepartner for his wife until she died many years ago, who is available to facilitate an online support group. If you have access to a computer and the internet, and are interested in getting more information about this group, please contact Louise LeBlanc at 416 227-1200 ext. 3304 or louise.leblanc@parkinson.ca

Sharing Dance 2015

What is it? The National Ballet School (NBS) has launched a program designed to teach dancers and non-dancers alike the joy of dance. Their motto: learn to, love to is embodied in the program designed to teach people that learning to dance can be a painless experience and that the result can be a lot of fun. NBS works with some of Canada's best choreographers to create a routine that is broken down in steps for people to learn. Follow along online as part of their video series, participate real time in a webcast based class, or even register and visit the ballet school for live instruction. Then, be a part of the event with people who learned just like you as part of a huge group of dancers performing the same routine live.

Who is it for? Young people… and the young at heart. NBS' routine is designed to be learnable by everyone, and they've even created an adapted take on the same routine for those with mobility issues so it truly is suitable for everyone. In 2014, a Parkinson's dance troupe danced alongside more than 400 community participants in the main performance in Toronto.

What can you do? Learn to dance! Join us. Have fun. Failing that, share this information. Do you know students, teachers, or other youth that might take part? Share the sharing dance website and let them know that they can dance to make a difference. PSCNO is looking for interested dancers to support them through this event, either people living with Parkinson's and their carepartners in our support group network or those who would love to learn to dance and support them at the same time.

How do you get started? Register online at http://sharingdance.ca/Fundraise and access their instructional materials at http://sharingdance.ca/Routines.

What if I can't attend? No problem. NBS' interactive website is set up so that you can record a video of your performance (either on your own, or as part of a community showcase) and upload it to share it with other dancers from across the country. Not interested in video? That's ok, too. Learn along, and dance for the joy of doing so.

Where is the big performance? In Toronto at Yonge-Dundas Square on May 24. Last year's event was a lot of fun, and a great success. A video of the performance from 2014 is available at http://www.sharingdance.ca/Performances/.

Need more details? Contact Jon Collins (jon.collins@parkinson.ca; 800-565-3000 ext. 3370) to learn about the program and how to gain access to online training tools and in person sessions.

Stop & Smell The Tulips!

The ground has barely thawed but tulips are coming up in the **Hope in Bloom Tulip Campaign** which kicks off on Thursday April 2. Now in its thirty-first year, the campaign raises funds through the sale of fresh-cut and potted tulips during the month of April, which coincidently is Parkinson's Awareness Month. Across the region, dedicated volunteers will be selling beautiful tulips at TTC locations, shopping malls, office building concourses in addition to selling creatively to hobby clubs, dental offices and restaurants, to name a few—we challenge you to join a selling team. It's easy, it's fun, and it's rewarding! Not convinced, just ask one of our 200-plus volunteers! Last year, their contagious enthusiasm raised more than $140,000 to help ease the burden and to find a cure through research, education, advocacy and support services. In our busy world, we sometimes forget to stop and smell the flowers. This April, take time to *Stop And Smell The Tulips* at one of our Hope in Bloom locations. You won't be disappointed!

To join us, please contact Helen Wong 800-565-3000 ext. 3377 or helen.wong@parkinson.ca. Check out our tulip webpage at http://bit.ly/1z81NCc for details about the campaign.

Around the Region

Pedaling for Parkinson's

Join us for our 5th year in Parry Sound In support of the Pedaling for Parkinson's Research Grant July 10-12. Ride one, two, or three days—distances suitable for all abilities.

www.pedalingforparkinsons.ca

Lunchtime Chats with Sandie

Join Sandie on the second Tuesday of each month at noon for our monthly education presentation. Sandie will talk briefly about the theme of the month and then answer questions sent in by you. Please send in your questions to ahead of time to Debbie.davis@parkinson.ca.

You can connect to the call one of the following two ways (*you only need to access the call one way; if you do both you will have double audio playing*):

- On your computer, log into the call via the following link: http://parkinson.adobeconnect.com/sandie/. Once you have opened the link, choose to enter as guest and then turn on your speaker.
- To connect by phone, call our toll free number 1-866-850-3418 (Toronto callers may dial 416-915-8692), and the participant code is 9415905.

2015 Education Sessions

Caring for Ourselves and Each Other

Belleville Education Session
Pathways to Support: where to get the help you need
Wednesday May 27, 9:30–11:45 a.m., Quinte Wellness Centre, Belleville ON
Panel of speakers (TBD)
This is a free event but registration is required. Please email diane.newmanreed@parkinson.ca or call 800-565-3000 ext. 3315 to register.

Toronto Summer Series #1
Tuesday, June 2, 7–9 p.m., PSC Conference Centre
"Share The Care" –how to stay at home and share the care with family and friends
This is a free event but registration is required. Please email helen.wong@parkinson.ca or call 1-800-565-3000 ext. 3377 to register.

Toronto Summer Series #2
July 7, 7–9 p. m., PSC Conference Centre
Community Support –homecare, an agency's perspective on elder planning
This is a free event but registration is required. Please email helen.wong@parkinson.ca or call 1-800-565-3000 ext. 3377 to register.

Toronto Summer Series #3
August 4, 7–9 p. m., PSC Conference Centre,
Caregivers' Personal Journeys –caregivers share their experiences with care, placement, etc
This is a free event but registration is required. Please email helen.wong@parkinson.ca or call 1-800-565-3000 ext. 3377 to register.

Collingwood Education Session
Tuesday, October 13, 1–3 p.m., Taoist Tai Chi Collingwood, 58 George St.
This is a free event but registration is required. Please email amanda.stanton@parkinson.ca or call 800-565-3000 ext. 3371 to register.

Niagara Parkinson's Health Fair
Saturday October 17, 10 a.m.–4 p.m.,
Holiday Inn, 327 Ontario Street, St. Catharines
Speaker: Dr. Barbara Connelly, MDS Hamilton ON- Managing Your PD
There will be a small charge; registration id required. Please email karen.dowell@parkinson.ca or call 800-565-3000 ext. 3376 to register.

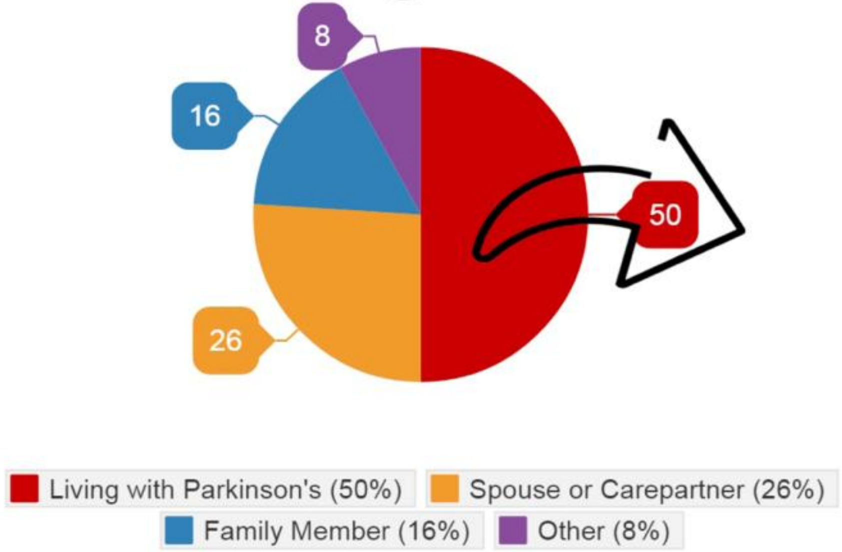
Toronto Fall Session
October 27, 6–9 p. m., Toronto Botanical Gardens
Panel Discussion (speakers TBD)
This is a free event but registration is required. Please email helen.wong@parkinson.ca or call 1-800-565-3000 ext. 3377 to register.

North Education Session—Details to follow
~~Saturday October 17, 10 - 4~~
~~Holiday Inn, 327 Ontario Street, St. Catharines~~
~~Speaker: Dr. Barbara Connelly, MDS Hamilton ON- Managing Your PD~~
~~Cost: $15 per person, registration required Please email karen.dowell@parkinson.ca or call 800-565-3000 ext. 3376~~

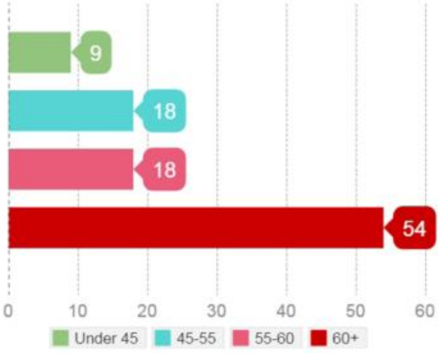
2014 Membership Survey

Thank you to all those who participated in our 2014 Membership Survey. Results are shared below and have impacted PSCNO's planning for the year ahead. The 2015 is available April 1-May 30 and is accessible at: www.parkinson.ca/cnosurvey or by contacting PSCNO.

Reason for Connecting with the organization



Age of Diagnosis



Time since Diagnosis

TOP Topics of Interest

- SUPPORT GROUP INFORMATION
- GENERAL PD INFORMATION
- PARKINSON SOCIETY SERVICES
- CONFERENCE and EDUCATION
- MEDICATION

90% of members rated serivces as Very Good or Excellent

> *"I have never failed to get an excellent response to any inquiries. [PSCNO] is a great team to work with."*

49% Volunteer

65% Know how to volunteer

46% Donate

68% Involved with Chapter or Support Group

61% Aware of events from their Support Group

53% Attended Conference or Education Session

Our Mission

Parkinson Society Central & Northern Ontario works in partnership with Parkinson Society Canada and eight other regional partners across Canada to ease the burden and find a cure through support services, education, advocacy, and research.

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Toronto, ON   M2P 2A9
www.parkinsoncno.ca
800-565-3000 or 416-227-1200
Charitable No: 10809 1786 RR0001

LiveWire is published three times annually: in the spring, the summer, and the fall. Expect our spring edition in March, our summer edition in August, and our fall and winter edition in November.

The **LiveWire** newsletter is published to provide helpful information to people affected by Parkinson's in Central & Northern Ontario. It is not meant to provide medical advice; readers should contact their doctors in all matters relating to health concerns and/or medication.

We welcome your feedback on current and past issues, as well as suggestions and submissions for future issues. If you have a story, a poem, or an article that you would like to submit for editorial consideration, please email the editor at livewire.editorial@parkinson.ca.

Next submission deadline is June 12, 2015.

LiveWire is offered in both hard copy and electronic form. If you are reading this copy and would like to be added to our mailing list, or if you would prefer to receive the electronic edition, please contact livewire.subscriptions@parkinson.ca to be added to our email notification list or call 800-565-3000 ext. 3474.

WOULD YOU LIKE TO HELP EASE THE BURDEN?

Scarborough/Bolton/Lindsay/Brampton/Newmarket

We are looking for volunteers to facilitate monthly support groups to provide education and support to persons with Parkinson's, members of their families, and/or their caregivers in dealing with the challenges of living with the condition. We encourage group members to share experiences, ideas, and feelings; address challenges; develop supportive friendships; and receive current information about Parkinson's disease. These groups are held once a month, often during the day on weekdays. Training will be provided. Once training is completed, the commitment is for three–five hours per month. Experience in facilitation of groups or meetings is an asset. Active seniors are welcome!

Contact Louise LeBlanc at 416-227-1200 ext. 3304 or louise.leblanc@parkinson.ca

Did you know?

*LiveWire is offered in both print and electronic forms. If you would prefer to receive the electronic edition, please contact **livewire.subscriptions@parkinson.ca** to be added to our email notification list.*

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