

Parkinson

PULSE

Connecting people living with Parkinson disease in Alberta



The
UNIQUENESS
of Parkinson's



What would you do if someone was stealing valuable items from your loved one, little by little, piece by piece, over the years?

Would you sit back and do nothing? OR would you step up and do something about it?

Parkinson disease is a cunning thief, slowly stealing a person's ability to walk, talk, swallow and even smile – little by little, piece after piece.

**APRIL IS
PARKINSON'S AWARENESS
MONTH!**

Help us stop a thief and make a difference in the fight against Parkinson disease.

parkinsonassociation.ca/stopathief



Parkinson's Awareness Month

APRIL 2020



Parkinson's Awareness Month sees the global Parkinson's community coordinate efforts to raise awareness and funds for Parkinson's. Parkinson Association of Alberta participates by planning initiatives and sharing evidence-based information across the province.

What exactly is Parkinson's awareness?

As a general definition, Parkinson's awareness is about understanding:

- » what Parkinson disease and Parkinson's Plus Syndromes are;
- » what the impact of Parkinson's is on individuals, families and communities;
- » what can be done to help people living with and affected by by Parkinson disease and Parkinson's Plus Syndromes;
- » what people (individuals, families, communities) can do to have a positive impact in regards to Parkinson's.

Our 2020 Campaign

We are pleased to be bringing back our successful "Stop a Thief" campaign.



This campaign once again aims to highlight TWO important aspects of Parkinson disease. First, that Parkinson disease acts like a thief

stealing tangible items/pieces from people both living with and affected by Parkinson disease. And second, that there are things people can do to help "stop" this thief. Below we list some examples

Get Educated: Parkinson's can steal the ground right from under your feet. Knowledge is power and one of the most formidable ways to "stop a thief!" Parkinson Association's educational programs, information and resources ensure YOU have the knowledge necessary live well with Parkinson's or help your loved ones, residents, clients, staff or students do the same.

Get Support: One's sense of belonging, purpose, joy and stability can be stolen by Parkinson's. Parkinson Association offers a variety of support programs (support groups, one-on-one/family supportive counselling, peer mentoring) to help "stop" feelings of isolation, depression and anxiety, and help regain a sense of self and purpose.

Get Active: Parkinson's steals independence, and physical, vocal, social and cognitive ability. Participating in one or more active programs (physical, vocal, cognitive and social) helps "stop" the thief by providing tangible tools to stay active and live well.

Participate in and/ or Support Research: With the number of people being diagnosed with Parkinson disease set to double by the next decade; Parkinson's continues to "steal" people's futures at an alarming rate. With an eye on stopping the thief that is Parkinson's, researchers devote time, effort and energy to solving many aspects of the Parkinson's puzzle. Taking part in research trials and/or making a donation to research helps create a brighter future.



Volunteer or Make a Donation: You can also stop the thief that is Parkinson's with your gifts of time, talent and funds. To ensure Parkinson Association can continue to carry out the vital work we do we need your help! Volunteer your time or talent at one of our events or with our day-to-day operations. You can also make a donation or host a third party fundraiser.

Watch for more details on our website and social media platforms and in our weekly E-Updates over the coming weeks.





Parkinson Association of Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.

We welcome your comments, suggestions and questions. Email us at communications@parkinsonassociation.ca; or call us toll-free at **1-800-561-1911**.

Parkinson Pulse is available (both past and present issues) as a free download via our website. Hard copies are available for mail out to current Members who wish to receive one.

**Parkinson Association of Alberta
Head/Calgary Office**

120, 6835 Railway St SE
Calgary, AB T2H 2V6
T: 403-243-9901

**Parkinson Association of Alberta
Lethbridge Region**

T: 403-317-7710

**Parkinson Association of Alberta
Edmonton Office**

11209 – 86 St NW
Edmonton, AB T5B 3H7
T: 780-425-6400

**Parkinson Association of Alberta
Lloydminster Region**

T: 780-808-5006

**Parkinson Association of Alberta
Grande Prairie Office**

T: 780-882-6640

**Parkinson Association of Alberta
Medicine Hat Region**

T: 403-526-5521

**Parkinson Association of Alberta
Red Deer Region**

T: 403-346-4463



Articles and information contained in the Parkinson Pulse are provided solely for the readers' interest. Articles do not necessarily reflect the views of Parkinson Association of Alberta and are NOT intended as medical advice. Please consult your doctor or neurologist in all matters relating to health concerns or medication.

Would you like to see your company ad in the **Parkinson Pulse**?

Advertising rates and opportunities are available.

Contact:
communications@parkinsonassociation.ca





1 Parkinson's Awareness Month



4 The Uniqueness of Parkinson's



14 Events as Unique As You Are!

Winter 2020

IN THIS ISSUE...

Features

- 8 PHARMACOLOGIC TREATMENT**
- 10 SURGICAL OPTIONS IN PARKINSON DISEASE**
- 12 NONPHARMACOLOGIC APPROACHES: Treatments as Unique as You Are**
- 19 THEY ARE ATHLETES**
Boxing & Parkinson's

Every Issue

- 2 CONTACT US**
- 6 NEWS + UPDATES**
- 7 MY STORY**
Fight in Your Game
- 14 THIRD PARTY FUNDRAISING**
Events as Unique As You Are!
- 16 EVENTS + UPDATES**
- 17 AT A GLANCE: SUPPORT GROUPS**
- 20 LAST LOOK**
KNOCK OUT Parkinson Disease at the MAIN EVENT



The UNIQUENESS of Parkinson's

Written by: Brandi La Bonte

Tigers are unique and beautiful creatures in many ways; but one of the most unique aspects is that no two tigers have the same stripes. Stripe patterns vary by subspecies, range in color from light brown to black, and are not symmetrical on both sides. Like human fingerprints, a tiger's stripe patterns are unique to each individual.

You might be asking yourself how a tiger's uniqueness relates to Parkinson disease. Consider

this – one of the most frequent misconceptions is that everyone experiences Parkinson disease in the same way. This could not be further from the truth. In fact, like tiger stripes, every person's experience with Parkinson disease is unique.

Parkinson disease is a complex condition and unique to the individual on many levels – from early signs to diagnosis, presentation of symptoms, progression and of course, treatment options.

Parkinson disease early signs and symptoms may include:

- » **Tremor**
A tremor, or shaking, usually begins in a limb, often a hand or fingers. The limb may tremor when it's at rest.
- » **Slowed movement (bradykinesia)**
Over time, movement may slow, making simple tasks difficult and time-consuming. Steps may become shorter and feet may drag when walking. It may be difficult to get out of a chair, off a bed or out of a car.
- » **Rigid muscles**
Muscle stiffness may occur in any part of the body. This can be painful and limit range of motion.
- » **Postural instability**
Posture may become stooped, and/or there may be balance problems (possible falls).
- » **Loss of automatic movements**
A decreased ability to perform unconscious movements, such as blinking, smiling or swinging of arms when walking.
- » **Speech changes**
These may include speaking softly, quickly, slurring or hesitating before talking. Speech may be more monotone rather than presenting with the usual inflections.
- » **Writing changes**
It may become hard to write, and writing may appear small.



Take early signs of Parkinson disease as an example. Not everyone will experience the same early signs and symptoms. And complicating things further, these signs can be easy to miss, oftentimes because they (at least initially) are mild and occur infrequently.

When it comes diagnosis, there is no singular way to make a diagnosis. No single scan or blood test. Rather physicians look for various symptoms in combination with diagnostic tests. These tests may include those to rule out other potential causes for one's symptoms.

Not all people who have Parkinson's will experience all the symptoms (both motor and non-motor), and the severity of those symptoms often vary from person to person.

Different people experience progression at different rates, as well. Symptoms and responses to treatment vary from person to person, so it is not possible to accurately predict how Parkinson's will progress. For some people it may take many years for the condition to develop, for others it may take less time.

Did you know "the array of pharmacologic and surgical treatments available for the treatment of idiopathic Parkinson disease (PD) is broader than for any other degenerative disease of the central nervous system"¹?

There is currently no cure for Parkinson disease and no treatment has been proven to slow, stop or change the progression of Parkinson's. The goals of Parkinson disease treatment vary from person to person. Generally speaking however, the goal is to provide control/management of symptoms for

as long as possible while minimizing adverse effects and focussing on addressing the symptoms that undermine a patient's quality of life. Treatment options for Parkinson disease can be divided into three "categories": pharmacologic (medications), surgical, and nonpharmacologic (non-medication).

There is a common saying amongst those in the Parkinson's community that states:

"If you've met one person with Parkinson disease, you've met ONE person with Parkinson disease."

So while it is true that there are certain hallmarks of Parkinson disease; it's uniqueness – it's "stripes" – when it comes to individuals also holds true. Not everyone experiences Parkinson disease the same way. Some have difficulty with tremor, while others have no tremor at all but are very stiff and rigid. Some take their medications five or six times a day, while others take none. Some have been living with Parkinson's for 10-15 years without substantial changes, while others see significant changes in the same timeframe. They experience different non-motor symptoms and each "deals" with their Parkinson's in their own unique way. There are similarities to be sure, a tiger is still a tiger after all – but the stripes make it unique.

References

¹ Spindler M, Tarsy, D. Initial pharmacological treatment of Parkinson disease. Retrieved from (last updated 2019-11-20) <https://www.uptodate.com/contents/initial-pharmacologic-treatment-of-parkinson-disease#references>

NEWS + updates

Meet Our Newest Staff Member!

We are pleased to welcome our newest staff member, Lana Tordoff! Read on, as Lana introduces herself.



Hello everyone and welcome to the first edition of the Parkinson Pulse for 2020. We are so delighted to be able to share this magazine in full colour and are grateful to our printing partner, Burke Group, for making that possible.

I am pleased to have this opportunity to introduce myself to you. I started with Parkinson Association in September 2019, having come from the YMCA of Northern Alberta and before that, Boys and Girls Clubs Big Brothers Big Sisters of Edmonton and Area. I began my career in the newspaper business and journeyed into the not for profit world – which has been and continues to be a truly rewarding experience. I bring with me a strong background in marketing, communications and fund raising. Working for small charities has also given me an opportunity to be knowledgeable and involved in all parts of operations. I also love building positive, focused and collaborative teams committed to the outcomes of their clients. This, and seeing the evidence of the impact Parkinson Association has on its community, is what drew me to work here.

For 2020 and beyond, we will be focused on increasing awareness of Parkinson disease, providing the best and most current information we can, listening to our members and offering supportive programs and opportunities that make a difference in people's lives. Critical to ensuring our success is raising the much needed funds that will allow us to be here for the people working so hard for the health and wellness of themselves and their families both today and in the future.

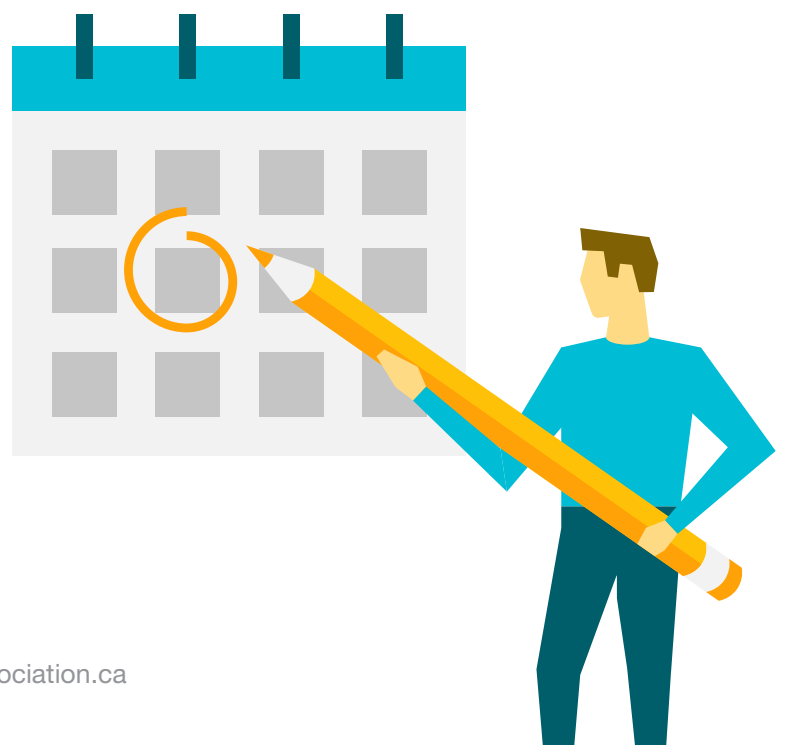
I am motivated daily by the people I've met so far and look forward to meeting many more who are connected with Parkinson Association of Alberta. You are part of a strong and vibrant community full of unique, compassionate and dedicated people. To our members and clients, thank you for your inspiration and determination. You are the reason we do what we do. To our volunteers, partners, donors and funders, thank you. You make the work of this organization possible and we are grateful for your gifts of time and financial resources. Being a part of this team is an honour.

With best wishes for the year ahead,

Lana Tordoff

Important Dates to Remember

- » All PAA Offices will be closed for **Family Day** on **February 17**
- » The **MAIN EVENT** aims to help KNOCK OUT Parkinson disease on **February 29**.
- » Parkinson's Awareness Month takes place in April with World Parkinson's Day taking place on **April 11**.
- » Save the date - **CARE Partner Summit** is **Saturday, May 16**.
Watch our website and E-updates for more information coming soon!



Parkinson disease and Parkinson's Plus Syndromes can be an isolating experience for those impacted by the disease; but the very act of sharing one's stories with others can counteract that isolation and so much more. Our "My Story" feature is an opportunity for YOU to share your unique story and experience with others. Your story serves as a powerful tool for creating a shared sense of understanding and community and for empowering yourself and others. It also can provide insight into YOUR unique experience that can serve as a bridge between the health/science world and the day-to-day realities of people living with and affected by Parkinson's.

Fight in Your Game

Written by: Linda Critchley

Several years ago my husband Keith's neurologist Dr Sarah Furtado suggested, for the third successive time, that we consider joining the Parkinson's Support Group in Cochrane. So we decided it might be time to give it a try. And after a phone call to Bob, a member of the support group, we began our relationship with Parkinson Association of Alberta, their team and the Cochrane Support Group. It was one of the most rewarding decisions we've made.

Keith has had Parkinson disease for 35 years, and living with Parkinson's for almost half your life, things can get really difficult. Sometimes it almost takes you to your knees. It's a long time to be living with a disease that affects almost every facet of your life. It can affect your ability to walk, to talk, to eat or whether you can ever drive. It affects your relationships with family and friends. Your spouse becomes a care partner and sometimes gets so enveloped in the being your caregiver that she forgets to be your wife as well. We were very fortunate, our relationship with family only got stronger. Parkinson disease affects your mood, mind and spirit. It affects how big your world is and what you can still do within it.

One of the things that Keith and I greatly enjoy together is watching sporting events on TV. I'm not sure how many of you had the phenomenal opportunity to watch the US Open of Tennis last September. A nineteen year old Canadian girl named Bianca Andreescu, who had never before played in a tennis major, defeated the great Serena



Williams. Serena Williams -- winner of 24 majors! After the heart stopping match, during the victory speeches, something was said that resounded deeply with me and that was to participate in a great undertaking you can only succeed by having "fight in your game".

Having fight in your game is what the journey with Parkinson disease is all about. It takes an awful lot of fight to deal with Parkinson's. And there are some very special people in that fight; my husband Keith is one of them.

Parkinson Association of Alberta helps us to keep that fight in our game. They provide support, education, resources, advocacy and promote research. They promote physical activity and healthy living through our Movers & Shakers program run by Joanne at Spray Lakes Rec Centre. They provide information and speakers at our annual Hope Conference. Messages from the Hope Conference speakers that stay with you. Messages that stick.

The people from Parkinson Association of Alberta know how to just listen to you. And sometimes there are moments in time, when just having someone who listens, is the most important thing in the world. They are a team of emphatic dedicated professionals. Because of them we have our support group and the friendships we've made in our group go way beyond our meetings. They last for years. They are a very important part of our fight.

FOLLOW US



/ParkinsonAssociationofAlberta



@PDAssocAB



parkinsonassociationofalberta



Pharmacologic TREATMENT

Written by: Brandi La Bonte

All persons with Parkinson disease will eventually need to take medications. There are currently no disease modifying drugs for Parkinson disease; however there are treatments that offer significant symptom relief of the motor symptoms. The impaired movement and motor symptoms attributed to Parkinson disease are caused by the loss of dopamine; as such, the core Parkinson's medications are aimed at replenishing or simulating dopamine to combat these symptoms.

While it may not be necessary to immediately start drugs to treat PD symptoms; when symptoms start to interfere with quality of life or the ability to function, it is time to think about medication. For some people, this may be soon after the symptoms appear and for others it may be some time later. The decision to start taking drugs is best made in discussion with one's neurologist or treating physician.

Determining what medications to prescribe, how much and how often can be tricky as there are a lot of variables to consider. In addition to how an individual responds to certain medications and/or dosages there are other factors to consider. For example, *"Treatment of early disease generally differs from later stages when various complications occur. It is also influenced by the patients' age. Younger patients usually develop motor complications earlier than older patients and these symptoms can be severe. On the other hand dementia is less common in younger patients who may better be able to tolerate individual but potentially complicated drug regimens that would be inadequate for older patients."*

The major medications available for the treatment of Parkinson disease include²:

Levodopa (L-dopa)

Levodopa is the most effective treatment for the motor symptoms of Parkinson disease. It works by replacing the dopamine in the brain. And, since dopamine is incapable of crossing the blood-brain barrier; levodopa is typically combined with either carbidopa or benserazide which helps the levodopa get into the brain where it is then changed into dopamine. Levodopa may be used alone or in combination with other Parkinson's drugs.

Levodopa formulations available in Canada include:

- » levodopa/carbidopa (*Sinemet*) - most common brand name form of levodopa
- » levodopa/benserazide (*Prolopa*)
- » levodopa/carbidopa with entacapone (*Stalevo*)

Dopamine agonists

Dopamine agonists mimic the effects of dopamine. They essentially trick the brain into responding as if there was dopamine in the brain. Dopamine agonists may be used as the first medication to treat Parkinson disease symptoms or in combination with other Parkinson's drugs.

Dopamine agonists available in Canada include:

- » apomorphine – subcutaneous injection (*Movapo*) or sublingual film
The apomorphine options are designed to move people rapidly from an OFF to an ON state. Both options have been approved for use in Canada, but are still making their way to market.
- » bromocriptine (*Parlodel*) - less commonly used than the others
- » pramipexole (*Mirapex*)
- » ropinirole (*Requip*)
- » rotigotine (*Neupro transdermal patch*)

Monoamine oxidase (MAO) B inhibitors

MAO-B inhibitors block an enzyme that breaks down dopamine in your brain. This leaves more dopamine available for your brain to use. MAO-B inhibitors may be used to control symptoms in early PD or in combination with other PD drugs.

MAO-B inhibitors available in Canada are:

- » Selegiline (*Eldepryl*)
- » Rasagiline (*Azilect*)

Anticholinergic agents

These drugs may be used to help correct the imbalance of the chemical acetylcholine in the brain resulting from a decrease of dopamine. They may help with slowness, tremors and rigidity.

Anticholinergics available in Canada include:

- » trihexyphenidyl (*Artane*)
- » benztropine (*Cogentin*)

Amantadine

This drug is used primarily to help reduce involuntary movements (dyskinesia) that may be a side effect of levodopa (it is also an antiviral drug used to treat the flu). Amantadine (Symmetrel) alone does not help PD symptoms.

Catechol-O-methyl transferase (COMT) inhibitors

COMT inhibitors block an enzyme that breaks down levodopa before it can be turned into dopamine. This allows more dopamine to be available to be used by the brain. COMT inhibitors alone do not help PD – they must be used with levodopa. They help levodopa work more smoothly. They can be added if your dose of levodopa is not working for long enough (end-of-dose deterioration) or the effect 'wears off' before your next dose is due.

COMT inhibitors available in Canada include:

- » entacapone (*Comtan*)
- » in combination entacapone/levodopa/carbidopa (*Stalevo*)

Everyone with Parkinson disease is unique and as such treatment is highly individualized – tailored to the individual's specific needs right from the beginning and as the disease progresses.



References

- 1 Münchau A, Bhatia KP. Pharmacological treatment of Parkinson's disease. *Postgraduate Medical Journal* 2000;76:602-610.
- 2 Parkinson Association of Alberta. *PD & Medication: Medications Commonly Used to Treat PD*. 2019-11.



SURGICAL OPTIONS IN PARKINSON DISEASE

*Written by:
Brandi La Bonte*

When medications alone are not enough to control the symptoms of Parkinson disease and/or when extreme motor fluctuations impede optimum functioning, surgical options may be considered as treatment. Surgical procedure options for Parkinson disease include deep brain stimulation (DBS) and lesioning surgeries (thalamotomy, pallidotomy and subthalamotomy) – which are both types of brain surgery; and Duodopa which is an alternative medication delivery system. Surgical procedures can provide some people with better control of their symptoms, but they are not a cure. One's Parkinson's will continue to progress and most people will still need to take some medication.

What are Lesioning Surgeries?

Lesioning involves making targeted damage (a lesion) to some of the cells in a specific area of the brain that contribute to the symptoms of Parkinson disease. These are named after the region of the brain targeted and include thalamotomy, pallidotomy and subthalamotomy. Lesioning surgery can be an effective treatment for Parkinson's, but with irreversible side effects and the development of other treatments (ie: DBS) it is not as common a treatment option as it once was.

What is Deep Brain Stimulation?

Deep brain stimulation functions like a pacemaker for the brain. Electrodes are surgically implanted deep into a precisely targeted area of the brain that controls movement; these electrodes then produce electrical impulses that affect certain cells and chemicals within the brain resulting in symptom improvement. The amount of stimulation is controlled by a pacemaker-like device placed under the skin in one's upper chest with a wire (that travels under the skin) connecting this device to the electrodes in the brain. Just how, exactly, DBS works is

still somewhat of a mystery; with many possible answers, research is essential and ongoing.

Who is it for?

Not everyone who has Parkinson disease is a candidate for DBS surgery. Typically, candidates are those with moderate to severe Parkinson's symptoms who are unable to get their symptoms under control with medication. Ideal candidates are those who have had PD for five or more years, are continuing to experiencing on/off fluctuations, and are still responsive to PD medications. DBS is not recommended for individuals who have balance, walking, or freezing issues that are not improved by medication; suffer from confusion, disorientation, or other cognitive issues on a daily basis; or who have other serious health conditions. It is important to acknowledge that DBS does not replace medication; however, often times dosages can be reduced once desired programming levels are obtained.

About the DBS Procedure:

The surgery is done while the patient is awake, first one side – then roughly a week later the other side. The patient will go home for two weeks without the neurostimulator turned on. During the following two weeks, the system is turned on with the electrical impulses being sent from the device up along the extension wire and into the brain. The impulses generated by the device interfere with, and block, the electrical signals that cause Parkinson's symptoms. Programming of the neurostimulator is done on an out-patient basis and is completed by a DBS nurse. Multiple programming visits may be required within the first 6 months of receiving DBS surgery. The procedure is projected to last for multiple years with a general rule of thumb being that DBS will remain effective so long as Parkinson's symptoms respond to dopaminergic meds.



DBS Side Effects:

As with any surgical procedure, there is the potential for complications. Temporary or reversible complications associated with DBS include changes in memory, thinking, and mood patterns, seizures, infection, problems with movement and speech, along with headaches, dizziness, tingling, and electrical jolt sensations.

What is Duodopa?

Duodopa encompass both the pharmacologic and surgical components of Parkinson disease treatment. Utilizing the very effective levodopa/carbidopa combination, but delivering it in gel form; the medication is delivered into a person's system via a small portable pump and tube (called percutaneous endoscopic gastrostomy jejunal tube or PEG-J tube) that connects directly into the jejunum or upper area of the small intestine. This process allows the body to receive medication simultaneously and continuously for 16 hours throughout the day, which allows the amount of drugs in the blood to be more constant, reducing disabling motor fluctuations (ie: ON/OFF periods).

Who is Duodopa for?

Not everyone is a candidate for this treatment option; those with a hypersensitivity or allergy to levodopa/carbidopa and those who have a history of stomach and/or intestinal problems, including though not limited to swelling, obstructions, impactions, or their pancreas prevents placement of a tube are not a good candidate for Duodopa. Duodopa is a more effective treatment for people with advanced Parkinson's, when treatment with other medications no longer deliver satisfactory control of symptoms.

About the Duodopa Procedure:

Doctors may choose to give a trial of the medication by placing a temporary tube through the nose into the small intestine before moving forward with the procedure of PEG-J placement. This will be used to see how well someone responds to the medication, as well as reach the best dose for the symptoms experienced. Once the pump is started, a larger dose is given in the morning to quickly reach the correct amount of medication needed, followed by a continuous delivery of medication throughout the day until bedtime. The medication itself is contained in a hard plastic cassette that is attached to the pump allowing the gel to be pumped directly into the small intestine. There is daily care and cleaning required at the insertion site and the tube to reduce any chance of infection. Doctors will control the dosage and treatment plan by programming the pump and may be adjusted as required.

Duodopa Side Effects:

In all medications and/or surgery there can be side effects. As this medication is delivered using a pump-tube delivery system, complications may occur from the surgical procedure, the tube and the medication itself. The following are the most common side effects are: pain at the incision site, redness, potential for infection, upset stomach and weight loss. These risks can be minimized with good communication and regular contact with your doctor.

Though the idea surgical procedures can be intimidating, these innovative technologies have proven effects for those suffering from Parkinson's; talk to your neurologist if this treatment is something you might be interested in.

Nonpharmacologic Approaches:

Treatments as Unique as You Are

Written by: Brandi La Bonte



Nonpharmacologic (as with pharmacologic and surgical) approaches will not cure Parkinson disease.

That said, they are helpful in maintaining and potentially improving the overall quality of life and well-being of people with Parkinson's. The approach or approaches you undertake depends on the challenges and or symptoms you are experiencing. Thus creating a treatment plan as unique as you are! Nonpharmacologic approaches include:

Physiotherapy

A physiotherapist/physical therapist can be a vital resource to help maintain mobility and balance and prevent and manage pain. They assess, diagnose and treat difficulties with movement and daily function by prescribing therapeutic exercise and customized plans to improve mobility for daily life.¹

Occupational therapy

With occupational therapy problems in the areas of self-care, work and leisure are addressed. An occupational therapist provides advice and instruction on adaptive equipment, safety awareness, energy conservation and mobility issues. They also assess home situations and can provide appropriate guidance on adaptive equipment and home adaptations.¹

Speech/voice therapy

Speech and voice issues are common occurrences for people with Parkinson's. Speech-Language Pathologists (SLP) are a high calibre resource that can help with speech and voice issues (as well as swallowing issues). The Lee Silverman Voice Treatment (LSVT) program is a well-documented approach and, there are also a number of current and past research projects that have studied the benefits of singing for people with Parkinson's.

Mental and/or emotional support

The impact of Parkinson's is multidimensional, affecting not only the individual diagnosed, but their loved ones. Effects vary from person to person and with a range that often includes one or more of the following: progressing physical limitations, depression, anxiety, increased stress, emotional problems, a decline in confidence, and changes to social life/status and issues relating to family dynamics. Accessing appropriate support when needed from a licensed therapist, clergy member, Client Services Coordinator or even a family member or friend is vital to maintaining good mental and emotional health.

Exercise

Research indicates that regular exercise may improve many aspects of the physical decline of Parkinson's such as gait, balance, tremor, flexibility, and motor coordination. And, it's not just the physical, motor symptoms of Parkinson's that benefit from exercise. Studies also show that regular exercise reduces stress, anxiety and feelings of depression. Exercise can also have a positive effect on cognitive, sleep and constipation issues.

Cognitive training

Research indicates people with Parkinson's (as well as care partners/aging adults in general) may benefit from incorporating a cognitive component into their healthy living plan/goals. For example: engaging in challenging cognitive tasks (puzzles, reading, memory games, etc) can help protect against age-related declines in thinking. It should be noted however that "the starting point for a cognitive training, training strategy and training frequency is unknown and currently under investigation."²

Education

Education contributes to health and well-being by equipping people with knowledge and skills for problem solving, and helps provide a sense of control and mastery over life circumstances. And it improves people's ability to access and understand information to help keep them healthy.

References

¹ Parkinson Association of Alberta. PD Health Care Team. 2013-12.

² Witt K, Kalbe E, Erasm R, Ebersbach G. Nonpharmacological treatment procedures for Parkinson's disease. *Nervenarzt*. 2017 Apr;88(4):383-390. doi: 10.1007/s00115-017-0298-y.



Please fill out and mail to PAA Calgary Head Office
120, 6835 Railway St SE, Calgary AB
T2H 2V6

Personal Information

Mr. Mrs. Miss Dr.

First Name: _____ Last Name: _____

Address: _____

City: _____ Prov: _____ Postal: _____

Phone: _____ Email: _____

- Person Living with PD Spouse/Partner has PD Family Member/Friend Professional Health Provider
- I would like to learn more about volunteering
- I would like to receive email communications from Parkinson Association of Alberta (including newsletter, updates & information)

Membership

Membership is \$25 annually and runs from January 1 to December 31.

- I wish to BECOME a member I wish to RENEW my Membership
- I would like my Parkinson Pulse Magazine mailed to me

Donation

Donations of \$20 and up will be receipted.

I wish to make a DONATION in the amount of: \$ _____

In Memory of _____ In Honor of _____

Please send a notification of this gift to (name and address): _____

Payment

Enclosed please find my cheque (made payable to Parkinson Association of Alberta)
or cash for \$ _____

Please bill my: Visa Mastercard American Express

Name on Card: _____

Card Number: _____ Expiry: _____ CVD: _____

THIRD PARTY Fundraising

Events as Unique As You Are!

Written by: Alicia Jeffery



Have you ever chosen to eat at a restaurant, attend a sporting event or shop at a store because they were fundraising for a charity that was important to you? Or as a family attended a wedding or hosted a birthday party where the gift was donation to a charity of choice? What about hosting a garage, car wash or bake sale or participating in jeans day, yoga or spin class where proceeds go to a cause close to you?

These are examples of third party fundraisers. By definition, a third party event is a fundraising initiative organized by an individual, community group, club, or business for the purpose of raising money for or on behalf of a cause or initiative. People (and businesses) have been inspired to put on and support third party fundraisers for decades (probably even centuries) to help support causes or initiatives they believe in. Hospitals, schools and parks get built. Equipment gets purchased, programs get funded or, like in the case of Terry Fox, funds are raised for research. And, with more technical tools (online, social media, etc.) at one's disposal, people are more empowered than ever to support causes near and dear to them.

Cilantro and Chive in Lacombe recently hosted a third party fundraiser in the form of a charity burger where proceeds from the sale of this burger went to Parkinson Association. Guest chef, local Home Hardware owner, Tyler Nowochin created a burger in memory of his father who had Parkinson's. Tyler's creation raised over \$1,500 dollars!

A third party event is defined as one where:

- » The event is planned and organized by an outside party (ie: an individual, family and/or business)
- » The revenue raised minus expenses is designated to Parkinson Association of Alberta
- » Our name is only used in advertising to state Parkinson Association of Alberta as the designated recipient of the event proceeds
- » Parkinson Association of Alberta staff involvement is minimal
- » Parkinson Association of Alberta only issues charitable tax receipts for donations made payable directly to Parkinson Association of Alberta (ie: cheques) and/or for cash donations where appropriate receipting information is provided (ie: amount, name, address and phone number)

How to host your own Third Party Fundraiser

1. Brainstorm a fundraising event (we can help with ideas!)
2. Get ready for your event: Set a date, plan the logistics and share your event with your circles of influence!
3. We can help by providing (if appropriate):
 - a) Parkinson's information brochures, donation bins, banners and our logo
 - b) Promotion of your event to our Parkinson's Community through our regular marketing channels (social media, e-blasts and internal communications).
4. Have a great event! Don't forget to post photos and tag us on social media!
 - a) **Facebook:** [ParkinsonAssociationofAlberta](#)
 - b) **Instagram:** [@parkinsonassociationofalberta](#)
 - c) **Twitter:** [@PDAssocAB](#)

Third party events can take place anywhere and at any time of the year. No particular date in mind? Parkinson Awareness Month is always a good fit and is just around the corner (04-2020)! Third party fundraisers are great for creating unique and inspiring events. You have the flexibility and creative freedom to plan a fundraiser that is truly meaningful to you! Have an idea? You can reach out via email (ajeffery@parkinsonassociation.ca) or by calling toll-free **1-800-561-1911**.

2019 THIRD PARTY EVENTS

Thank You To Everyone Who Hosted

Calgary & Area

- ATB Financial (*Till Campaign at various locations*)
- Burwood Distillery (*cocktail for a cause*)
- Calgary Expo (*Back to the Future Ticket campaign*)
- Freehold Brewery
- Half Hitched Brewery
- Highland Wine & Spirits (*Give Back Campaign*)
- Tamarack Jack Honey & Meadery
- YYC Cycle Spin Studio

Edmonton & Area

- Alley Kat Brewery
- Blind Enthusiasm (*Pint for Parkinson's*)
- Boston Pizza Kingsway
- Brewster's (*Jingle Bones*)
- Highland Wine & Spirits (*Give Back Campaign*)
- New Norway School
- Table Top Café (*Play for Parkinson's*)

Grande Prairie & Area

- Broken Tine Orchard

Lethbridge & Area

- Backstreet Pub & Pizza
- Dave Simmons Fort
- Mocha Caba Bistro
- Movie Mill
- Pops' Pub (*Pint for Parkinson's*)

Lloydminster & Area

- 4th Meridian Brewery
- Ribstone Creek Brewery
- Three Trees Tap & Kitchen

Red Deer & Area

- Blindman Brewery
- Bo's Bar and Grill
- Cilantro & Chive Restaurant
- Cupcakes for a Cause
- Siding 14 Brewing Co
- Troubled Monk Brewery



EVENTS + updates

UPCOMING EVENTS *For more information on our upcoming events, please visit our website at www.parkinsonassociation.ca*



Parkinson Association Launches Province-Wide 50/50 Raffle

Purchase a 50/50 Raffle Ticket for YOUR chance to win up to **\$10,000!**

Throughout the month of February, we are running a province-wide 50/50 raffle.

Tickets are **1 for \$20** or **3 for \$50**

Get your tickets today:

- » toll-free 1-800-561-1911 (ask for Lori)
- » direct 780-425-6400 (ask for Nicola)
- » or speak to your Regional Staff Member

Increase Your Donation's Impact by 50%

To kick off 2020 we are excited to announce that Bayshore Home Health's charitable arm ~ Bayshore Foundation ~ will match 50% of donations received this **February** *up to \$20,000!!

It's great math and an even greater result with funds raised going towards support services for people living with and affected by Parkinson disease and Parkinson's Plus Syndromes in Alberta!

\$5,000 raised will become \$7,500. \$10,000 will become \$15,000. \$20,000 becomes \$30,000 and \$40,000 becomes \$60,000 all thanks to the Bayshore Foundation! Don't let this generous matching opportunity slip away!



Third Party Event

Saturday, April 11 – Yoga Santosha in Calgary will be hosting a fun and active fundraising event for Parkinson Association of Alberta – Watch our social media and E-Updates for details.

SUPPORT GROUPS

The listings appearing in this issue were correct as of press time; please check your Regional section of our website for the most up-to-date information.

ALBERTA		1-800-561-1911
ARTA CHARITABLE FOUNDATION TELE-SUPPORT GROUP		
3 rd Wednesday	10:00 am – 11:00 am	Advance registration is required please call
CALGARY REGION		403-243-9901
AIRDRIE		
3 rd Tuesday	10:00 am – 11:30 am	Cam Clark Ford – 1001 Highland Park Blvd
CALGARY		
1 st Tuesday – Northwest	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
1 st Thursday – Northeast	10:00 am – 11:30 am	Ascension Lutheran Church – 1432 - 19 St NE
2 nd Tuesday – Southeast	10:00 am – 11:30 am	PAA Calgary Office – 120, 6835 Railway St SE
3 rd Tuesday – Care Partners	1:30 pm – 3:00 pm	PAA Calgary Office – 120, 6835 Railway St SE
3 rd Thursday – Southwest	10:00 am – 11:30 am	Riverpark Church – 3818 - 14A St SW
3 rd Saturday – Parkinson's Plus Syndromes	12:00 pm – 2:00 pm	Bass Pro Shop Mtg Rm – 261055 Crossiron Blvd
4 th Tuesday – Southeast	10:00 am – 11:30 am	PAA Calgary Office – 120, 6835 Railway St SE
4 th Tuesday – Young Onset	7:00 pm – 9:00 pm	Hope Lutheran Church – 3527 Boulton Rd NW
CANMORE		
2 nd Thursday	1:30 pm – 3:00 pm	920 Fairholme Dr
COCHRANE		
2 nd Thursday	10:00 am – 11:30 am	St. Andrew's United Church – 128 – 1 st St SE
NANTON		
4 th Thursday	10:00 am – 11:30 am	St. Cecilia's Catholic Church – 2308 – 19 th St
STRATHMORE		
1 st Thursday	1:30 pm – 3:00 pm	Hope Community Church – 245 Brent Blvd
EDMONTON REGION		780-425-6400
CAMROSE		
2 nd Wednesday	3:30 pm – 5:30 pm	Bethel Lutheran Church – 4102 – 73 St
EDMONTON		
1 st Wednesday – South	1:00 pm – 3:00 pm	Rutherford Heights – 949 Rutherford Rd
1 st Thursday – Care Partners	10:00 am – 12:00 pm	PAA Edmonton Office – 11209 – 86 St NW
3 rd Wednesday – Central	7:00 pm – 9:00 pm	PAA Edmonton Office – 11209 – 86 St NW
FORT SASKATCHEWAN		
4 th Tuesday	1:00 pm – 3:00 pm	Pioneer House – 10102 - 100 Ave
LEDUC		
4 th Tuesday	6:30 pm - 8:30 pm	Telford House – 4907 - 46 St
PARKLAND (SPRUCE GROVE/STONY PLAIN)		
4 th Thursday	10:00 am – 12:00 pm	Stony Plain – 107, 4613 – 52 Ave
SHERWOOD PARK		
2 nd Tuesday	1:00 pm – 3:00 pm	Bethel Lutheran Church – 298 Bethel Dr



AT A GLANCE SUPPORT GROUPS

While many of our Support Groups run monthly, September through June, some do run year-round or have summer dates. Please check your Regional section of our website for the most up-to-date information.

EDMONTON REGION (Cont.)		780-425-6400
ST. ALBERT		
3 rd Tuesday	10:00 am – 12:00 pm	St. Albert 55+ Club – 7 Tache St
WESTLOCK		
Last Monday - (Mar, Jun, Sep, Dec)	1:30 pm – 3:30 pm	Smithfield Lodge – 10203 97 St
GRANDE PRAIRIE REGION		780-882-6640
GRANDE PRAIRIE		
2 nd Wednesday	2:00 pm – 3:30 pm	Grande Prairie Care Centre – 9705 – 94 Ave
LETHBRIDGE REGION		403-317-7710
LETHBRIDGE		
3 rd Thursday	2:00 pm – 4:00 pm	Lethbridge Senior Citizens Org. – 500 – 11th St S
LLOYDMINSTER REGION		780-808-5006
BONNYVILLE		
3 rd Tuesday	10:30 am – 12:30 pm	Neighbourhood Inn – 5011 – 66 St
LLOYDMINSTER		
2 nd Monday - Care Partners	10:00 am – 11:00 am	Southridge Community Church – 5701 – 41 Street
4 th Tuesday	2:00 pm – 4:00 pm	Southridge Community Church – 5701 – 41 Street
VERMILION		
2 nd Tuesday	1:00 pm – 3:00 pm	Continuing Care – 5720 – 50 Ave
MEDICINE HAT REGION		403-526-5521
MEDICINE HAT		
4 th Tuesday	1:30 pm – 3:00 pm	Crossroads Church – 1340 – 22 St SE
RED DEER REGION		403-346-4463
CASTOR		
4 th Tuesday - (Feb, Apr, Jun, Aug, & Oct)	1:30 pm – 3:30 pm	Paintearth Lodge – 4501 – 55 Ave
LACOMBE		
4 th Wednesday	10:00 am – 12:00 pm	Wolf Creek Community Church – 4110 Hwy 12
OLDS		
2 nd Wednesday of the month	1:30 pm – 3:30 pm	Sunrise Village – 5600 Sunrise Cres
RED DEER		
3 rd Wednesday of the month	10:00 am – 12:00 pm	Davenport Church of Christ – 68 Donlevy St
ROCKY MOUNTAIN HOUSE		
2 nd Thursday - (Jan, Mar, May, Sep & Nov)	2:00 pm – 4:00 pm	Immanuel Lutheran Church – 5236 – 54 St
THREE HILLS		
1 st Wednesday - (Feb, May, Aug & Nov)	1:30 pm – 3:30 pm	Community Drop In Centre – 414 – 5 St S

FOLLOW US

 /ParkinsonAssociationofAlberta

 @PDAAssocAB

 parkinsonassociationofalberta



THEY ARE ATHLETES

Boxing & Parkinson's



We sat down with Roland Labbe, proprietor of Avenue Boxing (where our first boxing program began – and is still going strong today) in Edmonton to talk about boxing, Parkinson disease and where it all began. Today Parkinson Association of Alberta, along with our incredible program partners, offer boxing as an active program in SIX communities across Alberta!

Parkinson Association of Alberta (PAA): Avenue Boxing was the first boxing program for people with Parkinson disease in Alberta. How did you first get involved with Parkinson Association of Alberta to bring this program to life?

Roland Labbe (RL): *At Avenue Boxing we came up with the idea after learning about a program running in the States founded by Mickey Ward, who was a well-known boxer, called Rock Steady Boxing. We approached you (Parkinson Association of Alberta) and you were really excited to partner up with us so we ran with it and it has really taken off.*

We worked with your physiotherapist to build the basics of the program and to learn about the challenges people with Parkinson's have. The program was built around basic boxing skills focusing on balance and flexibility.

PAA: One of the things that sticks with me most about our initial meetings in the early days of the program was how you kept referring to the clients as "athletes." How do you think that approach/mentality changes their perception and/or view of themselves?

RL: *We consider our clients as athletes because it helps them to feel they are a part of the program like any other boxer. We do not look at them as people with Parkinson's we look at them as actually being athletes. They accept that and love the fact that they ARE athletes in a boxing program!*

PAA: Beyond the research that has been done on the positive impact of exercise (including boxing) for people with Parkinson disease, what do you think the positive benefits are? What have you observed?

RL: *The program has huge benefits as far as agility and physical awareness, but the biggest positive impact is they can*

actually see the difference the exercises make in their everyday life – physically, mentally and emotionally. It makes them stronger. The camaraderie that has developed between the athletes is a great plus to the program after a workout they meet down the street for coffee and have developed great friendship through the gym.

PAA: Why did you feel that this was an important project to be involved in?

RL: *One of the reasons I feel strongly about the program is that my mother had Parkinson's so it really gave me a sense of accomplishment when this became such a great success.*

PAA: What would you say to those individuals with Parkinson disease who aren't sure if boxing is for them?

RL: *We had a lady who came out and was very tentative. She really did not want to participate. Once she tried a class she could not believe the difference it made and she is still there today and never misses a class. So even if you're not sure just come out and try it once you get into it you will love it.*

PAA: What about the ladies? While I know we've got ladies in many of our programs, there is still that stigma out there that boxing is a man's sport?

RL: *Boxing is not just for men; women's boxing has flourished over the past decade. Jelena Mrdjenovich, who is the WBC/WBA world Champion in her weight class, has brought female boxing to a whole new level! So we embrace any women who want to come out.*

PAA: Speaking of Jelena, we've got a new and exciting event coming up at the end of February – the MAIN EVENT!! How did you get involved in this event?

RL: *Since our boxing program has developed, Ken Brander (Rotary Club) and I started working on a boxing night. We pitched it to the Association and your team ran with it and turned it into what is going to be a phenomenal event. We're proud to help knock out Parkinson disease – at the event AND in our programs!*

KNOCK OUT Parkinson Disease at

THE ★ MAIN ★ EVENT



Presented by **Parkinson Association of Alberta & Bayshore Home Health** this *dress to impress* evening takes place **Saturday, February 29th, 2020** at the prestigious JW Marriott Edmonton ICE District.

The event will include **FIVE** fights, world class cuisine, live music and special guest **Jelena Mrdjenovich**, current WBC Featherweight Champion of the World and WBA World Champion!

Boxing Alberta and **Avenue Boxing** have partnered with us to bring together ten of the best amateur fighters - five fights - to help knock out Parkinson disease!

Jelena Mrdjenovich, whose professional boxing record includes 50 fights – 38 wins (19 by knockout), 10 losses and two draws - will cap the night off in style with what's sure to be an inspiring keynote that will leave guests wanting more.

THE FIGHT CARD

COLE BRANDER vs ALLAIN BALON

BRYAN BAZINET vs MUHAMMED MOGRAHBI

MARKIS BANAK vs SETH LABOUCANE

MARIA REN vs IRIS FRYINGPAN

EMIL SMITH vs TRISTEN DEVEAU

4 FIGHTS | LIVE & SILENT AUCTIONS | WORLD CLASS CUISINE | FANTASTIC CAUSE

SAT. FEB. 29TH 2020 JW MARRIOTT

THE
**MAIN
EVENT.**

PRESENTED BY

Bayshore
Home Health



Honouring Special Keynote Speaker

JELENA MRDJENOVICH

Current WBC/WBA
Featherweight World Champion

TICKETS
\$200



AVENUE BOXING CLUB



CORUS



MITY
Group Inc.

YEGFITNESS



Visit: parkinsonassociation.ca/the-main-event-edmonton | Or call 780.425.6400

 **Parkinson**
Association of Alberta

Charitable
FOUNDATION

Tele-Support Groups

Third Thursday of the month from 10-11 am. To register call: 1-800-561-1911

Talk with peers across Alberta living with and impacted by Parkinson disease and Parkinson's Plus Syndromes.




8th Annual
FLEXXAIRE PARKINSON
STEP 'N STRIDE
September 12 & 13, 2020

Volunteer at your local Walk:
volunteer@parkinsonassociation.ca



Need a listening ear?

 **Parkinson**
Association of Alberta

Participate in our Peer-to-Peer Program

Our Peer-to-Peer program connects you with individuals who understand issues stemming from Parkinson disease and Parkinson's Plus Syndrome.

These telephone conversations can be one time or up to six (6), 1 hour sessions.

For more information on this program and on how you can be matched with a peer please

Call 1-800-561-1911 or email info@parkinsonassociation.ca

