

Parkinson

# PULSE

Connecting people living with Parkinson disease in Alberta



## **PARKINSONISM UMBRELLA**



**My Story P.4**

Happy 3rd Duodopa Anniversary

**Cover Story P.6**

The Parkinsonism Umbrella



ALBERTA RETIRED TEACHERS  
**Charitable FOUNDATION** **TELE-SUPPORT GROUP**

TO TALK WITH OTHERS ACROSS ALBERTA ABOUT  
LIVING WITH PARKINSON DISEASE AND PARKINSON PLUS SYNDROMES

Tele-Support Group takes place the 3rd Thursday of every month  
via telephone conference call from 10AM – 11AM.

We are also pleased to launch a special  
“Parkinson Plus Syndromes” Tele-Support Group

December 14 from 10AM – 11AM

Pick up your phone to connect to the support you need  
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FOR MORE INFORMATION OR TO REGISTER CALL TOLL-FREE  
**1-800-561-1911**



## Peer to Peer Program

### NOW RECRUITING

Our new Peer to Peer Program matches experienced client Mentors with a “MENTEE” who needs a listening ear, understanding of issues stemming from PD, and moral support from a peer who can offer lived experience, personal wisdom and encouragement.

Peer support is done via telephone and can be a one-time conversation or up to six (6), 1 hour sessions.



For more information or to apply to be a MENTEE, please email [info@parkinsonalberta.ca](mailto:info@parkinsonalberta.ca)

Fall 2017

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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.

*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.*

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Please visit our website:  
[www.parkinsonalberta.ca/aboutus](http://www.parkinsonalberta.ca/aboutus) to view our staff and board list.

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.

We welcome your comments, suggestions and questions. Email us at [communications@parkinsonalberta.ca](mailto:communications@parkinsonalberta.ca); or call us toll-free at **1-800-561-1911**.

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

*Advertising rates and opportunities are available.*

**Contact:**  
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780-425-6400



## From the Desk of **THE CEO**

The impact of Parkinson disease is multidimensional and ever changing, affecting not only the individual diagnosed and their loved ones, but the community and health care system as well.

In order to successfully adapt to living with a Parkinson's diagnosis, an individual and their family undertake behavioral, social and emotional changes. Communities and health care systems must look to their offerings, processes and policies to ensure they too have a positive impact on life with Parkinson's. The same concept applies to Parkinson Association of Alberta as we grow and adapt to meet the transitional needs of all our clients. We must be both effective and efficient while maintaining the core tenants of who we are and what we do.

Over the past two years Parkinson Association, along with many other not for profits and Albertans as a whole, have been faced with a substantial downturn in the economy. And, despite successful fundraising endeavours – like this year's Flexxaire Parkinson Step 'n Stride™ (pg 20) – we find ourselves in a deficit situation. This together with the challenges of increased demand for support and services and the evolving needs of our clients have Parkinson Association of Alberta endeavouring to revamp our service delivery model.

To address these challenges we have had to and will continue to undertake measures to ensure all clients continue to have access to the support and services that are vital to living well with Parkinson disease.

The most noticeable measure was the decision to close storefront offices in Lethbridge, Medicine Hat and Red Deer (effective December 1, 2017). To be clear, this does **NOT** mean a loss of support and services, rather these regions will move to the same format as our Lloydminster Region and utilize home offices while still providing the same level of support and services as before. This cost-saving measure will free up considerable funds that will be directed towards support and services and deficit reduction in those regions.

Another noticeable change will be the move of the Calgary/Head Office. Our lease has expired and with no

option to renew, we are in the process of seeking out new space to accommodate our growing needs.

As we head into 2018 we will look for ways to reach Albertans living with and affected by Parkinson disease in an efficient and effective manner.

We will increase our knowledge and capacity to assist those with Parkinson Plus Syndromes (pg 6). We will continue to strive to provide credible, high calibre education opportunities via our Speaker Series (which will be available online) and our Hope Conference which will take place May 2018 in both Calgary and Edmonton.

Utilizing technology will help us ensure no matter where one lives in our vast province, there is access to specialized support. Our newly sponsored Alberta Retired Teachers Association Foundation Tele-Support Group, PD Helpline and online offerings (Ask the Experts, information and resources) are prime examples. We will delve even further however, looking into tele-health and Skype-like opportunities.

We will focus our fundraising efforts on our key initiatives like our tulip and poinsettia campaigns, golf tournament, sip sample support/Malts 'n Barley events, and of course, our Flexxaire Parkinson Step 'n Stride™. We will remain committed to furthering Parkinson's research in Alberta through our Champions of Hope Campaign that aims to raise \$5 million in four years.

We will continue to work with all levels of government, Alberta Health Services, corporations, community stakeholders and researchers to pave the way towards a brighter future for those affected by Parkinson's.

A large portion of Parkinson Association of Alberta's success over the past forty-plus years can be contributed to our incredible client base; and also our hard-working Board and staff. We work diligently to ensure our clients feel supported and raise the profile of Parkinson disease in Alberta through exceptional client services, determined fund developers, dedicated communications and administrative staff, and thoughtful leadership.

We look forward to an even more successful 2018.



John Petryshen, CEO  
Parkinson Association of Alberta

# HAPPY 3<sup>RD</sup> DUODOPA ANNIVERSARY

*John & Elaine Laidler*

**D**iagnosed in 2004, John had been working in a logging camp as a mechanic. During this time, John began working with a physical therapist at the Glenrose, was introduced to the PWR! program through the CRIS clinic, and began speech therapy. Elaine was determined to help her husband, learning the exercises and information and coaching him along. John went back to work, this time to Fort McMurray. His symptoms continued to progress and he began to struggle to get in and out of his truck and even walk to the office. John retired in 2011.

Elaine began to advocate for different medications, treatment, neurologists—something that would help her husband. His community neurologist referred him to the Movement Disorders Program where he began to work with Dr. Suchowersky. John completed four different cycles of testing over a year when he and Elaine began to talk with Dr. Suchowersky about DBS and Duodopa. Further testing revealed that he was not a candidate for DBS.

John was told it would be a few months before he would receive the surgery for Duodopa but then received an emergency call. He got special permission from AHS to cover the costs. John was given the upper dose through his nasal cavity and "it was like magic." He walked "beautifully." "We all had tears in our eyes—even the doctor—because the original prognosis was not good." On November 27, 2014, John underwent surgery for Duodopa.

Prior to the surgery they were taught by the Duodopa nurse how to use the pump, where it went and why it went there. The surgery took about half an hour and John spent two days in hospital. He had no issues at all. The doctors set the original dosage and John was able to make his own adjustments, up or down by two. Both state the follow-up care was excellent, and each time John visited the clinic they would check the read out and adapt the pump as needed.

John and Elaine did have one mishap in which the tube came out and was leaking. Elaine called for help and wasn't able to receive guidance. Elaine shared that back then the emergency department did not know what Duodopa was or had any training to help them. She shared that now they have had training on and experience with Duodopa.

Today, John and Elaine continue to travel—scootering through the hills of the Cabot Trail in Nova Scotia and taking cruises. John feels he would not be walking if he had of stayed on his medications. Elaine said he was like a whole new person after he had the surgery.

*"It was joyous to watch, a Miracle!"*

John can now run up and down the stairs although he sometimes freezes. "It's worth it—amazingly worth it—it takes the worry of taking the medications off you. It's always there. There's a lot of freedom with it." Elaine shared "it is no big deal to carry it with you when you travel as long as you keep the medication cool." She shared that 'they' will send it to a Shopper's Drug Mart wherever you are and they will keep it in their cool storage until you arrive to pick it up. "It's a pretty great program." For John, it's given him a better lease on life.

**Happy 3rd Duodopa Anniversary  
John!**

# OUR DUODOPA JOURNEY

*Al & Lillian Rallison*

**AL** was officially diagnosed with Parkinson disease in July 2013, though he and his wife Lillian were quite convinced that was what was causing the symptoms prior to diagnosis. Al and Lillian were both still working at the time and both indicated that while they took the diagnosis "in stride", it took a "long time to get our heads wrapped around it." The couple had been looking forward to retirement – a chance to travel; and, in Lillian's case, she was still teaching at the University and had planned to work for a bit longer. Both wanted to be able to spend more time at their lake property. Lillian stated that she was and is grateful for Al's laid back personality, though "it (the disease) can test your ability to face the challenges that life presents."

By summer 2016 Al was taking upwards of 10 pills a day every couple of hours and having a lot of "off" periods. It was at that time that Dr. Sarna began a discussion about Duodopa. Al and Lillian spent six months pondering the choice that lay before them. Some of the fears they had were that it was an invasive procedure and worry that the aesthetics of the equipment would lead to some significant self-consciousness. While they were pondering, they were able to chat with a couple who had already gone through the process, which both found incredibly helpful. Together they made the decision to move forward with the procedure.

In spring 2017 they began working with Eric Tse, the Duodopa nurse at the Movement Disorders Program in Calgary who had discussions with them about the process. They asked to have the procedure put off until the fall of 2017 in order to enjoy the summer and have a few more months to process.

In early September 2017 Al underwent the first step of the process which was to have, under sedation, a temporary tube inserted through the nose into the small intestine. This step helped to ensure a positive

response prior to surgery. The plan was to keep the tube in for a couple of days, but it worked so well that the plan was adjusted to keep the tube in for six days and Al and Lillian were able to carry on with the Duodopa for that six-day period. Lillian stated "it was great because you could see that this actually was going to make a difference!" A couple weeks later, Al underwent surgery.

Like the temporary tube, the positive result was immediate. Al states that a few minor adjustments to dosage were made, but all-in-all it was a resounding success. On a day-to-day basis Al notices that he experiences less "ups and downs" throughout the day, can eat whatever he wants, and though he's not sure if it's a positive effect of the Duodopa or not, he no longer experiences constipation—which was a significant issue prior. Both he and Lillian noticed that they are much more social now than they were before the procedure.

Working with the pump on a daily basis has not posed any challenges whatsoever. With Lillian's background as a nurse and Al's keen sense of independence it did not take long for a system that works for them to fall into place. They've experienced a few issues with medication delivery, but other than that things have gone smoothly.

As for words of wisdom or advice for others considering the procedure the couple states that people should talk with others who have had the surgery as both found it quite helpful and helped them to see the benefits. They also both state that the opportunity to try the temporary tube BEFORE surgery was a positive as they were able to witness first-hand what the benefits would be.

*When asked if they would do it all over again, Al's response was "I would have done it sooner."*

## THE PARKINSONISM UMBRELLA

**P**arkinsonism is the umbrella term used to describe a group of conditions that feature Parkinson's-type symptoms including tremors, stiffness and slowness of movement (bradykinesia).

Most people (about 85%) with parkinsonism have Idiopathic Parkinson's, more commonly known as Parkinson disease or PD. It is referred to as "idiopathic" because the cause is unknown in the majority of people diagnosed. The remaining 15% of people with Parkinsonism have other, more rare conditions.

So how do physicians determine whether a diagnosis is Parkinson disease or something else?

As with Parkinson disease, the diagnosis is often a clinical one relying on an examination by a neurologist knowledgeable in these conditions. And, with symptoms presenting in a like-manner, the diagnosis may not be obvious at a first physician's visit and an accurate diagnosis may take time.

One of the more telling differences is that people with Parkinson disease are apt to have a positive response to the common Parkinson's medication, levodopa, while people with other causes of parkinsonism usually do not respond or tend to respond less well to the medication. When physicians see unusual symptoms and/or a poor response to levodopa they may start to question whether the person has Parkinson disease. When this happens, a person may hear their physician use the following terms:

- **Secondary Parkinsonism**
- **Atypical Parkinsonism**

These terms are not diagnoses but simply indicate that the person probably does not have "ordinary" Parkinson's.



Secondary parkinsonism refers to a group of disorders that have features similar to those of Parkinson disease but have a different etiology (cause). Atypical parkinsonism refers to a group of neurodegenerative disorders other than Parkinson disease that have some features of Parkinson disease but different clinical features and a different pathology (structural and functional changes).

### SECONDARY PARKINSONISM

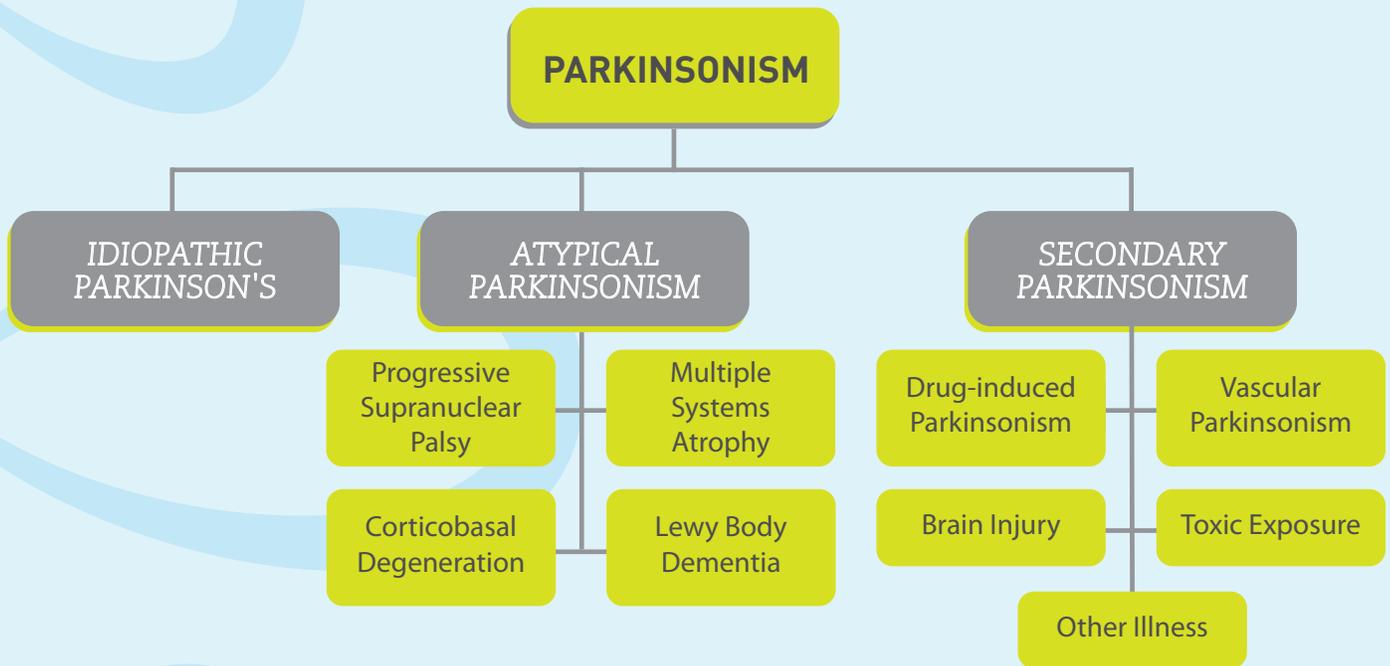
In secondary parkinsonism the symptoms are caused by certain medications, a different nervous system disorder, or another illness. These can include instances of brain injury or toxic exposure such as carbon monoxide poisoning. Two other significant examples are:

- **Drug-Induced Parkinsonism**
- **Vascular (Arteriosclerotic) Parkinsonism**

#### Drug-induced Parkinsonism

A small number (around 7%) of people develop Parkinsonism after taking certain medications.

Any drug that blocks the action of dopamine (dopamine antagonists) is likely to cause parkinsonism. Antipsychotics (also known as neuroleptics), used to treat conditions like schizophrenia or significant depression, are thought to be the biggest cause of drug-induced parkinsonism. It should be noted however that



although offending drugs cause parkinsonism in a dose-related manner, there is large variation in individual sensitivity.

Drug-induced parkinsonism may often continue for weeks or months after stopping the drug that is the cause, though some will recover within hours or days.

For treatment of antipsychotic behavior in people with Parkinson disease both quetiapine (Seroquel®) and clozapine (Clozaril®) are considered safe medications.

### Vascular (Arteriosclerotic) Parkinsonism

Vascular parkinsonism is a form of parkinsonism in which the parkinson-like symptoms (slow movements, tremor, difficulty with walking and balance, stiffness and rigidity) are produced by one or more small strokes, rather than by a gradual loss of dopamine. Many physicians believe that high blood pressure and diabetes are the most likely causes, while also noting that stroke and heart disease may also be a factor.

It can be difficult to distinguish vascular parkinsonism from Parkinson disease as symptoms typically present as they would in Parkinson disease. However, these symptoms would likely appear suddenly, would not progress and, usually affect the lower part of the body more so than the upper part.

Treatment of vascular parkinsonism involves working to minimize conventional stroke risk factors such as smoking, high blood pressure, high cholesterol, obesity, etc.

### ATYPICAL PARKINSONISM

Atypical parkinsonism, often referred to as Parkinson Plus Syndromes, is a group of movement disorders that shares many of the prominent physical symptoms of Parkinson's with additional features that are key to distinguishing them from idiopathic Parkinson disease. The following are the four most common types of Parkinson Plus Syndromes:

- Progressive Supranuclear Palsy (PSP)
- Multiple System Atrophy (MSA)
- Corticobasal Degeneration (CBD)
- Lewy Body Dementia (LBD)

These syndromes can be more difficult to diagnose because symptoms mimic other conditions, particularly Parkinson disease. It is important to differentiate Parkinson Plus Syndromes from Parkinson disease because both treatment and prognosis are different. The similarities and differences are outlined in more detail in a separate article within this issue.

# NEWS

+ updates

## REMINDER

**Effective December 1, 2018,** Parkinson Association of Alberta's storefront offices in Lethbridge, Medicine Hat and Red Deer will transition to home offices.

This does NOT mean a disruption of services, and Clients in these regions will continue to have access to the support and services necessary to live well with Parkinson's.

## Hope Conference

**RETURNS TO CALGARY  
AND EDMONTON**

**MAY 2018**

DETAILS ARRIVING JANUARY 2018 AND EARLY  
REGISTRATION BEGINS FEBRUARY 2018!

## HAVE YOU VISITED OUR YOUTUBE CHANNEL?

Watch our latest Speaker Series presentations, or view our Faces of Parkinson's videos from the comfort of your home and the convenience of your laptop, tablet or cellphone!

[www.youtube.com/user/ParkinsonAlberta](http://www.youtube.com/user/ParkinsonAlberta)

## RENEW YOUR 2018 MEMBERSHIP!

It is only with your thoughtful, ongoing support that we can continue to offer the best in support, programs, education and funds for research both today and tomorrow. When you become a member, you are not just "buying a membership", you are investing in the future of Parkinson disease in Alberta!

Join friends old and new at our annual  
**HOLIDAY CELEBRATIONS**  
taking place this November and December.

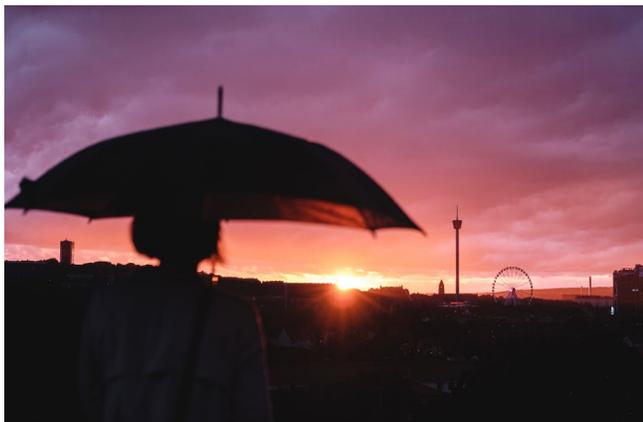
Contact your Regional Office or view your  
Program Calendar for more details

Please note all Parkinson Association of Alberta Offices will be closed December 25, 2017 through January 1, 2018. We will return to regular operating hours on January 2, 2018. Have a safe and happy holiday season!

**DID YOU KNOW:**

**that some people with Parkinson disease report feeling increased artistic creativity, with some research indicating that some actually develop a passion for the visual arts and/or writing that wasn't present before?** Whether you have Parkinson disease, or love someone who does letting your creativity flow can be a good way to reduce stress and encourage relaxation.

**T**his issue's piece was written by Linda Kenney when she was first diagnosed and is a reflection of how she felt at the time. She shared her poem with her support group and many people identified with it. Linda has had Parkinson disease for 20 years now and not only participates in many PAA offerings, but is a great resource and support to many as well.



## *My Lonely World*

Who said life would be easy  
As she struggles through each day  
With questions that go unanswered  
About the disease that takes away

Her life was blessed with children  
And to them her love bestowed  
She finds it difficult to explain  
How the illness affects her so

She feels so isolated  
No one can understand  
What's happened to this person  
Who seemed to in command

Her behaviour is unfamiliar  
This person they do not know  
If they could only understand  
They'd know she's hurting so

Her "friends" do not want to hear it  
For they think her life is grand  
And that she is taking advantage  
Of a much envied disability plan

They laugh at her emotions  
They ridicule and mock  
They pretend that they're her friends  
When she knows that they are not

They jeer at her obsessions  
They scorn her every move  
And wonder how her family  
Can tolerate her moods

But who is she to grumble  
And why would she complain  
To them she looks "just wonderful"  
As she struggles to hide her pain

They see the roles are changing  
She's not as strong as before  
The tough façade she is wearing  
Is losing its fearless roar

Her future is uncertain  
Those days ahead she fears  
Of what is happening to her body  
As it slowly disappears

She asks the Lord to guide her  
Through the difficult days ahead  
To accept her limitations  
And forgive those who turn their head

Who said life was easy  
For this she is finding out  
Her journey is just beginning  
Her future is in doubt.

- *Linda Kenney*



Parkinson Plus Syndromes (atypical parkinsonism) is a term used to describe syndromes that share features similar to Parkinson disease but are distinctly different conditions.

In the broadest of terms, the main clinical features that distinguish Parkinson Plus Syndromes from Parkinson disease are:

- Limited or no response to levodopa
- Lack of or an irregular resting tremor
- Symptoms present on both sides of the body at onset
- Early issues with
  - Balance and falls
  - Cognitive issues
  - Speech and swallowing issues
- Faster progression

In this article we will delve into the four most common types of Parkinson Plus: Progressive Supranuclear Palsy, Multiple System Atrophy, Corticobasal Degeneration and Lewy Body Dementia.

## Progressive Supranuclear Palsy

Progressive Supranuclear Palsy, or PSP, is the most common atypical parkinsonism. It is also known as Steele-Richardson-Olszewski syndrome, named for the three Canadian physicians who first described the condition in 1964.

In terms of affecting particular parts of the brain, PSP is characterized by a tau protein buildup (Tauopathy) that affects the frontal lobes, brainstem, cerebellum and substantia nigra.<sup>1</sup>

### The Facts:

- Average onset is late 50s/early 60s
- Prevalence is 4 or 5/100,000

### Symptoms include:

- Vision problems, including:
  - trouble shifting gaze vertically (Supranuclear gaze palsy)
  - inability to maintain eye contact
- Early problems with balance and mobility, including a tendency to fall backward
- Early cognitive/personality changes
- Uncontrolled emotional outbursts (laughing or crying for no apparent reason)
- Speech often becomes slower and slurred and swallowing solid foods or liquids become quite difficult

**Treatment:** There is no specific medication to treat PSP directly, rather current treatment options focus on attending to the symptoms most prevalent (ie: sleep and mood issues). Some may find limited and/or temporary relief from levodopa when addressing issues of slowness, stiffness and balance issues. Botox injections may help with eye issues.

## Multiple System Atrophy

The second most common form of atypical parkinsonism is Multiple System Atrophy or MSA. At one time MSA was also known as Shy-Drager Syndrome to acknowledge early contributions of two physicians; Dr. Milton Shy (National Institutes of Health) and Dr. Glenn Drager (Baylor College of Medicine).

In terms of affecting particular parts of the brain, MSA is characterized by an abnormal accumulation of alpha-synuclein protein in brain cells (synucleinopathy) that affects the autonomic nervous system (the part of the nervous system that controls internal functions such as heartbeat, blood pressure, urination digestion), substantia nigra and at times the cerebellum.<sup>1</sup>

### The Facts:

- Average onset is 50-60
- Prevalence is 4 or 5/100,000

### Symptoms include:

- A significant drop in blood pressure when standing (postural hypotension) that can cause dizziness or fainting
- Bowel and bladder issues
- Parkinsonian symptoms including: slowness, stiffness, rigidity and balance issues
- Speech and swallowing difficulties
- Erectile dysfunction

- Dry mouth and skin
- Color and temperature changes in hands and feet

**Treatment:** There is no specific medication to treat MSA directly, rather current treatment options focus on attending to the symptoms most prevalent (ie: blood pressure and bowel/bladder issues). Some may find limited relief from levodopa when addressing Parkinsonian issues.

## Corticobasal Degeneration

Corticobasal Degeneration, or CBD, is the third most common form of atypical parkinsonism.

In terms of affecting particular parts of the brain, CBD is characterized by a rare tauopathy that typically affects one side of the body more than the other and makes it difficult for patients to see and navigate through space.<sup>1</sup>

### The Facts:

- Average age of onset is 50-70
- Prevalence is 1/100,000

### Symptoms include:

- Loss of ability to perform complex/coordinated movements (apraxia)
- Parkinsonian symptoms including: slowness and stiffness
- Rapid muscle jerks (myoclonus)
- An abnormal, fixed posture (dystonia)
- Involuntary movement of a limb and/or feeling like that limb is foreign or has a mind of its own (alien limb syndrome)
- Permanent shortening of muscles and/or joints (contracture)
- Speech and swallowing issues
- Cognitive and behavioral changes

**Treatment:** There is no specific medication to treat CBD directly, rather current treatment options focus on attending to the symptoms most prevalent (ie: contracture issues). Some may find limited relief from levodopa when addressing Parkinsonian issues.

## Lewy Body Dementia

Lewy Body Dementia, or LBD, is the second most common cause of dementia after Alzheimer's disease. It is not always considered parkinsonism. In terms of affecting particular parts of the brain, LBD is

characterized by an abnormal accumulation of alpha-synuclein protein in brain cells (synucleinopathy).<sup>1</sup>

### The Facts:

- Average onset is 50-80
- Studies indicate that LBD accounts for 10-20% of all dementias. However, no concrete data on prevalence is available at this time.

### Symptoms include:

- Parkinsonian symptoms including: slowness, tremors, stiffness, stooped posture, etc.
- Dementia (preceding or within one year of onset)
  - trouble shifting gaze vertically (Supranuclear gaze palsy)
  - inability to maintain eye contact
- Fluctuating cognition and alertness ("good" times vs "bad" times can fluctuate from day-to-day or moment-to-moment)
- Vivid visual hallucinations that are not a side effect of medications
- Sleep issues
- Hypersensitivity to neuroleptic medications

**Treatment:** The Parkinsonian symptoms in LBD often respond to levodopa. Similar to those with Alzheimer's, cognitive issues may be treated with cholinesterase inhibitors. Of significant note is that both movement and behavioral symptoms can be severely (and gravely) aggravated by older anti-psychotics (ie: Haldol, Compazine and Reglan).

## Prognosis

As with Parkinson disease, symptoms will progress over time; however symptoms tend to progress more rapidly in comparison to Parkinson's. Due to their rapid rate of progression, those diagnosed with a Parkinson Plus Syndrome are more likely to experience substantial disability within five years.

As a result of variations in progression, age, severity of symptoms, and an individual's overall health it is not possible to accurately predict life expectancy. However, in studies that have been undertaken the average life expectancy after diagnosis ranges between six to ten years. This is a marked difference from Parkinson disease wherein life expectancy is the same as those without Parkinson's.

## Non-Drug Management of Parkinson Plus Syndromes

Beyond medications, various therapies and supports are available to help relieve symptoms and improve quality of life.

- Physiotherapy can be used to help with movement and balance issues
- Occupational therapy may help to improve skills needed on a day-to-day basis
- Speech and language therapy can be utilized to assist with both speech and swallowing issues
- Counselling may be of benefit in helping to come to terms with a diagnosis, alleviate stress, create goals and action plans and empower one's self
- Support Groups can help erase feelings of isolation, provide peer support, and offer learning opportunities
- Physical, Speech/Voice, Cognitive and Social programming can offer opportunities to engage with others, keep active and live well

## For Family and Care Partners

The diagnosis of a Parkinson Plus Syndrome has a significant impact on those close to the person diagnosed. A rapidly progressing disability gives rise to an increasing need for care and support which can leave care partners and families feeling isolated and burnt-out. It is important for care partners and family to remember to take care of themselves as well. Asking for help when needed and setting self-care goals can be vital to reducing stress and improving caregiving.

Parkinson Association of Alberta provides support, services and programs for all people with Parkinsonism conditions (and their families) – not just those with Parkinson disease. These supports and services include Support Groups, one-on-one/family supportive counselling, education sessions, assistance in identifying and locating community and government resources, and much more. To find out more please contact your Regional Office, call us toll-free at 1-800-561-1911 or visit our website at [www.parkinsonalberta.ca](http://www.parkinsonalberta.ca).

### References:

1. [www.hopkinsmedicine.org/healthlibrary/conditions/nervous\\_system\\_disorders/atypical\\_parkinsonian\\_disorders\\_22,AtypicalParkinsonianDisorders](http://www.hopkinsmedicine.org/healthlibrary/conditions/nervous_system_disorders/atypical_parkinsonian_disorders_22,AtypicalParkinsonianDisorders)



**Don't live alone with Parkinson disease.**  
**We can help.**  
All you have to do is start the conversation.

## PD HELPLINE

**Call 1-877-243-9992**  
*Monday to Friday  
8:30 am till 4:30 pm  
Free from anywhere in Alberta*

# RESEARCH IN ALBERTA

Researchers around the world, including right here in Alberta, are working to identify and address various issues associated with Parkinson's. Clinical trials are a key component of research and are at the core of all medical advances. One of the biggest challenges associated with research (besides funding) is a lack of participation.

If you feel participating in a research study is something you are interested in, we encourage you to view the available opportunities to find out if there is a good match available for you. Please note that interested individuals are not necessarily guaranteed acceptance into a study. The information listed below is limited to generalities; to find out more about the research participation opportunities listed below, please visit our website at [www.parkinsonalberta.ca/callforresearchparticipants](http://www.parkinsonalberta.ca/callforresearchparticipants)

- **Comprehensive Assessment of Neurodegeneration and Dementia Study (COMPASS-ND Study)**

Who is eligible	People with Parkinson's
Type of Participation	Five onsite visits at the University of Alberta over twelve weeks

- **Neurophysiological and neuropsychological changes following motor imagery training in people with Parkinson Disease**

Who is eligible	Men with Parkinson's
Type of Participation	Six onsite visits at the University of Alberta

- **Efficacy and Safety of Deferiprone in Treatment-naïve and Non-treatment-naïve Patients with Parkinson Disease**

Who is eligible	People with Parkinson's between the ages of 18-80 who have been diagnosed within the last three years
Type of Participation	Nine onsite visits at the University of Alberta

- **Effects of Transcranial Magnetic Stimulation on Mild Cognitive Impairment in Parkinson Disease**

Who is eligible	
Type of Participation	Ten onsite visits at the University of Calgary over three months

- **Caffeine Habits, Smell-Ability, and Parkinson Disease**

Who is eligible	People with or without Parkinson's between the ages of 45-65
Type of Participation	Mail-in survey

- **Strength, Hope and Resourcefulness Program for People with Parkinson's**

Who is eligible	People with Parkinson's who have been diagnosed within the last five years
Type of Participation	Onsite participation at the University of Alberta for a six week program

- **Longitudinal Study of Mild Cognitive Impairment in Parkinson Disease**

Who is eligible	People with or without Parkinson's 60 years of age or older
Type of Participation	Eight onsite visits at the University of Calgary over three years

- **A Rural Perspective of Living with Parkinson Disease**

Who is eligible	People with Parkinson's and their care partners who live in Rural Alberta and have to travel greater than 50KM to see their physician/neurologist
Type of Participation	Location convenient to participant for a 45-60 minute conversation



# CHAMPIONS OF HOPE RESEARCH CAMPAIGN UPDATE

Supporting bright minds of today and tomorrow is the pillar of Parkinson Association of Alberta's Champions of Hope Research Campaign. Champions of Hope aims to promote the care and treatment of people with Parkinson disease and their care partners, enhance clinical research into the diagnosis and treatment of Parkinson disease, promote the education of people with Parkinson's, care partners, families and health professionals, and develop opportunities for study and interdisciplinary collaboration. The Campaign has a four year plan to raise \$5,000,000 for Parkinson disease research— a move which is unprecedented in Canada, where Parkinson disease research is underfunded but critically needed.

This past September, the Champions of Hope Committee hosted an afternoon in the intimate Opera Room at Teatro Ristorante in Calgary. The goal was to introduce donors and recognize significant contributions to the Champions of Hope Research Campaign. Among those in attendance were campaign chair, Bob Fisher, committee members Al Schreiner, David Banks, Doug Critchley, Brian Hein, and Hotchkiss Brain Institute Director, Keith Sharkey.



A sincere thank you to Mr. Hein, of Hein Financial Group, who made a generous \$50,000 contribution to the Campaign.

Parkinson Association of Alberta CEO, John Petryshen, was presented with a cheque for \$173,000 for Champions of Hope and spoke of the need for Parkinson disease research in Alberta. Mr. Petryshen stated, "Champions of Hope demonstrates to people living with Parkinson disease in our province, how serious we are about helping—not only with programs and services, but also by finding new treatments, enhancing care, and ultimately finding the cause of the disease and a cure."



The Committee also wishes to thank and acknowledge Brent and Deborah Hesje (Edmonton) from Fountain Tire for supporting the Champions of Hope Research Campaign with a \$10,000 donation.

Parkinson Association of Alberta wishes to thank everyone who has supported the campaign this year. Champions of Hope can reach its goal only with the help of philanthropic donors and volunteers who continue to lend their support. To find out how you can support a brighter future in Parkinson disease call toll-free **1-800-561-1911**.

# EVENTS

## + updates

### UPCOMING EVENTS

*For more information on our upcoming events, please visit our website at [www.parkinsonalberta.ca](http://www.parkinsonalberta.ca)*

#### Petals for Parkinson's (formerly Parkinson Alberta Grows)

Our beautiful mini-holiday poinsettias are back and sure to brighten up any room! Available for \$8/pot these blooms are available in our Calgary, Edmonton, Lethbridge, Lloydminster and Red Deer Regions. This year, we are looking to expand our sales during the Petals for Parkinson's Campaign by calling on friends to help us sell poinsettias to their own friends, families and colleagues and networks.

If you live in one of the participating regions and would like to help Parkinson Association of Alberta this winter, please call **1-800-561-1911**.

Save the date.

## GIVINGTUESDAY™

is November 28, 2017.

Sun	Mon	Tue	Wed	Thu	Fri	Sat
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

[www.GivingTuesday.ca](http://www.GivingTuesday.ca) | #GivingTuesdayCA

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Moment  
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### PAST EVENTS

#### 2017 Step 'n Stride Till Campaign

This year, Parkinson Association of Alberta got creative in our quest to have the most successful Flexaire Step 'n Stride Walk to date! At businesses in Grande Prairie, Red Deer, Medicine Hat and Lethbridge, we introduced our Step 'n Stride Till Campaigns! The communities rallied around Step 'n Stride to support and helped us to bring in almost \$1000 in additional donations across the province! Thanks to Save On Foods in Grande Prairie, Lethbridge and Red Deer and Sobey's and Smoothie Bacon Dogs in Medicine Hat for your support.

#### sip sample support - Medicine Hat

On October 14, 2017, over 80 guests attended our third annual **sip sample support** at Mario's Restaurant in Medicine Hat. Hosted by a fantastic local committee, Suzanne Curtin, Kimberley Knight and Donna Morgan, the event featured a four-course tasting menu with foods from France, Belgium, Spain and Italy and a custom paired fine wines, beers and spirits provided by Pacific Wine & Spirits. The evening raised almost \$25,000 that will go towards providing support and services in the Medicine Hat community.

#### Movie Mill - Lethbridge

A big thanks goes out to the Movie Mill in Lethbridge for selecting Parkinson Association of Alberta as their charity of choice for their Give Back Combo in October! Over 955 Give Back Combos were sold over the month and the Movie Mill proudly presented local Client Services Coordinator, Alicia Visser, with a cheque for \$955!



Thank you!

**Parkinson Association of Alberta has been proud to partner with our title sponsor, Flexxaire, on our Flexxaire Parkinson Step 'n Stride™ for the last four years.**

You may ask, what does being a title sponsor mean? Well, for most companies, it would mean writing a cheque and making sure their logo was on all the marketing materials for the event. But Flexxaire is different. Flexxaire shows they care about Albertans living with Parkinson's every day. They show they care by encouraging their employees to participate in Step 'n Stride and by being one of the top fundraising teams every year. Lastly, Flexxaire shows they care by showing up for Parkinson Association for Alberta when we need their help the most.

This year, our CEO, John Petryshen, had the honor of presenting Flexxaire with a token of appreciation from our Camrose Support Group. About her hand-pieced quilt, Connie Henderson from Camrose said:

*"The quilt is to be considered as a gift from the Camrose Step 'n Stride Committee as a whole. It was made as a means to give back and to express thanks to Flexxaire for their generous contribution that makes events like Step 'n Stride possible, especially in the smaller communities where hosting an event might not otherwise be viable."*



We'd like to send out a heartfelt thank you to Flexxaire, for not only being the title sponsor of Step 'n Stride, but for going far beyond what it means to be a sponsor. Thank you, Flexxaire for all you do to enhance the lives of Albertans living with Parkinson's.



## **We're excited to announce that we've opened sponsorship for the 2018 Flexxaire Step 'n Stride™!**

In 2017, Parkinson Association of Alberta celebrated the 5th Anniversary of Flexxaire Parkinson Step 'n Stride™ and raised over \$400,000 for Albertans living with and affected by Parkinson's! In 2018, we invite you to Step Up for Parkinson's by joining our provincial sponsor, Flexxaire Inc., in sponsoring the Flexxaire Parkinson Step 'n Stride™.

We would be happy to meet with you and talk with your organization about the benefits of participating with us. Please contact [info@parkinsonalberta.ca](mailto:info@parkinsonalberta.ca) for more information.

# SUPPORT GROUPS

While many of our Support Groups run monthly, September through June, please check with your Regional Coordinator to find out about December Groups. Please check your Regional section of our website for the most up-to-date information.

ALBERTA			1-800-561-1911
<b>TELE-SUPPORT GROUP</b>			
3 <sup>rd</sup> Thursday of the month	10:00 am – 11:00 am	Advance registration is required to receive call-in instructions & a passcode; call the above number.	
Dec 14 & Feb 8 – <b>Parkinson Plus (PSP, MSA, CBD, etc)</b>	10:00am – 11:00am	Advance registration is required to receive call-in instructions & a passcode; call the above number.	
CALGARY REGION			403-243-9901
<b>AIRDRIE</b>			
3 <sup>rd</sup> Monday of the month	10:00 am – 11:30 am	<b>Cam Clark Ford</b> – 1001 Highland Park Blvd	
<b>CALGARY</b>			
1 <sup>st</sup> Monday of the month	10:00 am – 12:00 pm	<b>Hope Lutheran Church</b> – 3527 Boulton Rd NW	
1 <sup>st</sup> Thursday of the month	10:00 am – 11:30 am	<b>Hope Lutheran Church</b> – 3527 Boulton Rd NW	
2 <sup>nd</sup> Monday of the month	10:00 am – 11:30 am	<b>McDougall United Church</b> – 8516 Athabasca St SE	
3 <sup>rd</sup> Monday of the month - <b>Care Partners</b>	1:30 pm – 3:00 pm	<b>PAA Calgary Office</b> – 102, 5636 Burbank Cres SE	
4 <sup>th</sup> Monday of the month	10:00 am – 11:30 am	<b>McDougall United Church</b> – 8516 Athabasca St SE	
4 <sup>th</sup> Monday of the month - <b>Young Onset</b>	7:00 pm – 9:00 pm	<b>Hope Lutheran Church</b> – 3527 Boulton Rd NW	
<b>COCHRANE</b>			
2 <sup>nd</sup> Thursday of the month	10:00 am – 11:30 am	<b>St. Andrew's United Church</b> – 128 – 1st St SE	
<b>NANTON</b>			
4 <sup>th</sup> Thursday of the month	10:00 am – 11:30 am	<b>St. Cecilia's Catholic Church</b> – 2308 – 19th St	
EDMONTON REGION			780-425-6400
<b>CAMROSE</b>			
2 <sup>nd</sup> Wednesday	3:30 pm – 5:30 pm	<b>St. Andrews Anglican Church</b> – 4713 – 50 St NW	
<b>EDMONTON</b>			
1 <sup>st</sup> Wednesday of the month - <b>South</b>	1:00 pm – 3:00 pm	<b>Rutherford Heights</b> – 949 Rutherford Rd	
1 <sup>st</sup> Thursday of the month - <b>Care Partners</b>	10:00 am – 12:00 pm	<b>PAA Edmonton Office</b> – 11209 – 86 St NW	
3 <sup>rd</sup> Wednesday of the month - <b>Central</b>	7:00 pm – 9:00 pm	<b>PAA Edmonton Office</b> – 11209 – 86 St NW	
3 <sup>rd</sup> Friday of the month - <b>North</b>	10:00 am – 12:00 pm	<b>Shepherd's Care</b> – 12603 – 135 Ave	
Dec 13 & Feb 14 - <b>Young Onset</b> (Under 50)	6:30 pm – 8:30 pm	<b>PAA Edmonton Office</b> – 11209 – 86 St NW	
<b>FORT SASKATCHEWAN</b>			
4 <sup>th</sup> Tuesday of the month	1:00 pm – 3:00 pm	<b>Pioneer House</b> – 10102 - 100 Ave	
<b>LEDUC</b>			
4 <sup>th</sup> Tuesday	6:30 pm - 8:30 pm	<b>Telford House</b> – 4907 - 46 St	
<b>PARKLAND (SPRUCE GROVE/STONY PLAIN)</b>			
4 <sup>th</sup> Thursday	6:30 pm – 8:30 pm	<b>Rehoboth</b> – 3920 49 Ave, Stony Plain	



<b>SHERWOOD PARK</b>		
2 <sup>nd</sup> Tuesday	1:00 pm – 3:00 pm	<b>Bethel Lutheran Church</b> – 298 Bethel Dr
<b>ST. ALBERT</b>		
3 <sup>rd</sup> Tuesday of the month	1:00 pm – 3:00 pm	<b>St. Albert 55+ Club</b> – 7 Tache St
<b>WESTLOCK</b>		
Last Monday of the month	1:30 pm – 3:30 pm	<b>Room 140, Provincial Bldg</b> – 2, 10003 – 100th St
<b>GRANDE PRAIRIE REGION</b>		<b>780-882-6640</b>
<b>GRANDE PRAIRIE</b>		
2 <sup>nd</sup> Tuesday of the month	2:00 pm – 4:00 pm	<b>Wildrose Manor</b> – 9358 – 70th Ave
<b>LETHBRIDGE REGION</b>		<b>403-317-7710</b>
<b>LETHBRIDGE</b>		
3 <sup>rd</sup> Thursday of the month	2:00 pm – 3:30 pm	<b>Lethbridge Senior Citizens Org.</b> – 500 – 11th St S
<b>TABER</b>		
2 <sup>nd</sup> Tuesday of the month	10:00 am – 12:00 pm	<b>Taber Public Library</b> – 5415 – 50 Ave
<b>LLOYDMINSTER REGION</b>		<b>780-808-5006</b>
<b>LLOYDMINSTER</b>		
4 <sup>th</sup> Tuesday of the month	2:00 pm – 4:00 pm	<b>Southridge Community Church</b> – 5701 – 41 Street
<b>WAINWRIGHT</b>		
1 <sup>st</sup> Wednesday of the month - <b>Care Partners</b>	7:00 pm – 9:00 pm	<b>Provincial Building</b> – 810 – 14th Ave
2 <sup>nd</sup> Tuesday of the month	2:00 pm – 4:00 pm	<b>Provincial Building</b> – 810 – 14th Ave
<b>MEDICINE HAT REGION</b>		<b>403-526-5521</b>
<b>MEDICINE HAT</b>		
4 <sup>th</sup> Tuesday of the month	1:30 pm – 3:30 pm	<b>Crossroads Church</b> – 1340 – 22 St SE
<b>RED DEER REGION</b>		<b>403-346-4463</b>
<b>CASTOR</b>		
Jan 30 & Mar 27	1:30 pm – 3:30 pm	<b>Paintearth Lodge</b> – 4501 – 55 Ave
<b>LACOMBE</b>		
4 <sup>th</sup> Wednesday of the month	10:00 am – 12:00 pm	<b>Wolf Creek Community Church</b> – 4110 Hwy 12
<b>OLDS</b>		
2 <sup>nd</sup> Wednesday of the month	1:30 pm – 3:30 pm	<b>Sunrise Village</b> – 5600 Sunrise Cres
<b>RED DEER</b>		
3 <sup>rd</sup> Wednesday of the month	10:30 am – 12:30 pm	<b>Davenport Church of Christ</b> – 68 Donlevy St
<b>THREE HILLS</b>		
Feb 7 & Apr 4	2:00 pm – 4:00 pm	<b>Community Drop In Centre</b>

*Hope Conference*  
**ALBERTA'S LARGEST LIVING WELL  
 WITH PARKINSON'S EVENT**

**MAY 2018**

DETAILS ARRIVING JANUARY 2018  
 AND EARLY REGISTRATION BEGINS  
 FEBRUARY 2018!





Please fill out and mail to PAA Calgary Head Office (address on page 2)

## 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: \_\_\_\_\_



## Last Look THAT'S A WRAP ON THE 2017 FLEXXAIRE PARKINSON STEP 'N STRIDE™!

A huge **Thank You** to all the Walkers, Volunteers, Sponsors, and Supporters of the 5th Anniversary Flexxaire Parkinson Step 'n Stride™! On September 9th & 10th, over 1800 Walkers and Supporters gathered together in communities across Alberta to help raise vital funds for Albertans living with and affected by Parkinson disease.

Though pledges will still be accepted until December 31, 2017, we are delighted to report that together we have raised over \$400,000 for Parkinson disease services, education, advocacy, and research in Alberta making 2017 Flexxaire Parkinson Step 'n Stride™ our most successful Walk to date!

This year we had more Walkers, more Sponsors, more Pledges, and more Support from Albertans than ever before! We want to sincerely thank everyone who came out to support us this September!

Here are the Flexxaire Step 'n Stride Totals from 2017:

Provincial Sponsorship	\$50,000
Bonnyville	\$3,986
Calgary	\$86,519
Camrose	\$22,796
Cochrane	\$33,095
Edmonton	\$114,180
Grande Prairie	\$13,479
Lethbridge	\$14,887
Lloydminster	\$21,639
Medicine Hat	\$18,253
Red Deer	\$21,689
<b>TOTAL</b>	<b>\$400,523</b>



We look forward to seeing you next year



for our 2018 Flexxaire Parkinson Step 'n Stride™ Walk Weekend on September 8th & 9th, 2018!



Thank You





# petals for parkinson's



Brighten someone's day and make a difference  
in the lives of those with Parkinson disease!



**\$8**  
/pot

Details available on our website now!  
[www.parkinsonalberta.ca/petalsforparkinsons](http://www.parkinsonalberta.ca/petalsforparkinsons)

