

# Parkinson **PULSE**

Connecting people living with Parkinson disease in Alberta



## Parkinson's 101



### **My Story P.4**

My Personal Journey with Parkinson's  
- It is Up To Me! - Ken Rowes

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### **Cover Story P.6**

Parkinson's 101



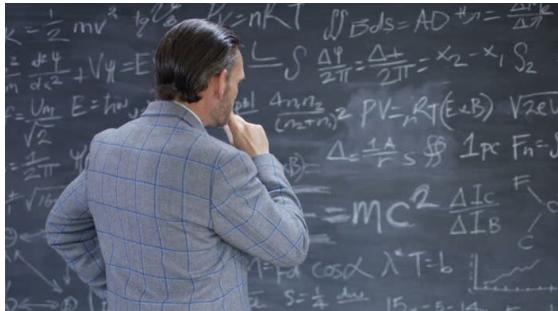
# STEP UP FOR PARKINSON'S **2018**

Step Up to Make a Difference for Parkinson's at our  
6th Annual Flexxaire Parkinson Step 'n Stride™ on  
September 8th & 9th!

**ONLINE REGISTRATION IS NOW OPEN!**

<http://www.parkinsonalberta.ca/stepnstride>





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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.**

## Parkinson Association of Alberta Head/Calgary Office

### Mailing Address

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

### Physical Address

310, 6807 Railway St SE

## Parkinson Association of Alberta Edmonton Office

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

## Parkinson Association of Alberta Grande Prairie Office

103, 10901 – 100th St  
Grande Prairie, AB T8V 2M9  
**T** 780-882-6640

## Parkinson Association of Alberta Lethbridge Region

PO Box 333  
T1J 3Y7  
**T** 403-317-7710

## Parkinson Association of Alberta Medicine Hat Region

PO Box 23063  
T18 4C7  
**T** 403-526-5521

## Parkinson Association of Alberta Red Deer Region

87, 6740 Johnstone Dr  
Red Deer, AB T4P 3Y2  
**T** 403-346-4463

## Parkinson Association of Alberta Lloydminster Region

**T** 780-808-5006

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:**  
[communications@parkinsonalberta.ca](mailto:communications@parkinsonalberta.ca)



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

Parkinson disease is a journey; one Parkinson Association of Alberta (PAA) has helped and is helping many individuals and families travel. Our staff meet new clients frequently as well as providing support to those who have been on the Parkinson journey for decades. We are confident in our ability to help every individual and family on their journey; though it is not always easy or possible to meet everyone's needs in one fell swoop. This is why PAA offers an array of support, programming, information and resource options.

In this issue we go "back to basics" in regards to Parkinson disease and Parkinson Association of Alberta as a whole. This issue will be an excellent tool for those new to Parkinson disease, Parkinson Plus Syndromes and/or PAA; and also a great refresher for those who have been affected by Parkinson disease for a while.

The "basics" of Parkinson disease typically start with questions...the main one being "what is Parkinson disease?" ([page 6](#)) In short, Parkinson disease is a progressive neurodegenerative brain disorder for which there is no known cause or cure. People of every race, economic class, and ethnicity can get Parkinson disease; and, while the average age of diagnosis is 56, PD can strike at any age with 5-10% of people with PD developing symptoms before the age of 40. It is the second most common neurodegenerative disorder after Alzheimer's disease.

It is possible to live well with Parkinson's? With medication ([page 14](#)) and good physical and mental health, it is possible to manage Parkinson's carefully and successfully.

What about care partners (and families)? While it is, of course, true that only one person physically receives the diagnosis; the ripple effect created can have a tremendous impact on the care partner and family ([page 10](#)). Care partners are an essential part of society. There are more than eight million caregivers in Canada; that is more than one in four adults. And, according to statistics from Caregivers Alberta, to replace all the care these individuals provide would cost \$66 billion per year!

What about the "basics" of Parkinson Association of Alberta – who are we, what do we do? I am reminded of a statement that was relayed to one of our staff by a client. In various phrasing, it is a sentiment that has been repeated many times over the years.

*"Nobody wants to get Parkinson disease; but I tell you what, I'm sure glad I got it here in Alberta."*

Parkinson Association of Alberta is proud to be the **ONLY** charitable organization to offer this level of comprehensive, high-calibre support and services to people living with and affected by Parkinson disease and Parkinson Plus Syndromes for over 40 years.

Our province-wide (and oftentimes extending past our borders) network provides support and education programs, information and referrals, and, health and wellness activities, and events to facilitate a better quality of life for individuals and families in the Parkinson's community.

We aim to innovate and inspire a brighter future in Parkinson disease by profiling research and committing vital funds via our Champions of Hope program ([page 13](#)). We also reach out to the public through presentations, media channels and stakeholder engagement to elevate awareness about Parkinson's and our offerings. It is this hands-on and all-encompassing structure that distinguishes Parkinson Association of Alberta from other organizations serving people with Parkinson disease.

This May will see the return of Alberta's largest Parkinson disease education event, Hope Conference for Parkinson's, to Calgary and Edmonton ([page 12](#)). This is one event that is designed to meet the needs of the entire Parkinson's community! Online registration for Hope Conference is now underway; as is online registration for our 6<sup>th</sup> annual Flexxaire Parkinson Step 'n Stride™!

It is possible to live well with Parkinson's. Parkinson Association of Alberta is here every day to provide individuals and families with the necessary support, information and resources to live well with Parkinson.

John Petryshen, CEO  
Parkinson Association of Alberta

# MY PERSONAL JOURNEY WITH PARKINSON'S – IT IS UP TO ME!

*Ken Rowes*

I first really noticed the symptoms in 2005 when I found it was difficult to walk. My right leg had trouble working. I went to my family doctor who sent me to a neurologist. He told me I had Parkinson disease and he would prescribe pills if I wanted them. That was the extent of his help. I went home and told my wife, who was looking out a window at the back yard, that I had Parkinson's. She did not even turn around. The blessing in all of this is that I got out of bad marriage that was over a long time ago.

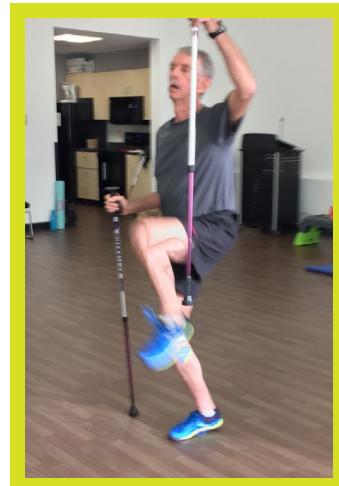
I was fortunate to get an appointment with a neurologist in Edmonton and that was a blessing. I told my children, friends and co-workers about my situation. At the time I was a Senior Vice President in a major organization. Fatigue had set in and I knew I could not keep working. My boss told me that it was up to me to decide when I was to go, that he would not ask me to leave.

After I retired I moved into a very nice condo where I met Doreen. We started to hang out together and became good friends. At the start I told Doreen that I had Parkinson's and I did not fully understand the implications of that. We stayed friends, however we fell in love too. I proposed to Doreen in the swimming pool at the condo. She said yes!

I know that I am so blessed. I was referred to the CRIS Clinic by my doctor and that was the start of my participation in PWR! (Parkinson's Wellness Recovery). I came home from those sessions and felt like I was bouncing off the walls with positive energy. Something very good was happening to me! The effects of the Parkinson's seemed to be backing off. Doreen and I joined Parkinson Association of Alberta (PAA) and have made many new friends there. We receive great support from PAA and I am fully engaged with the PWR! Program that happens at the Edmonton Office.

I am in better condition today than I was in 2005.  
I attribute this to:

- **Attitude**
- **Proper medication**
- **PWR! type exercise**
- **And the support of family and Parkinson Association of Alberta**



So how do I feel about all of this? My glass is half full, not half empty.

Doreen is the main reason that I am doing so well, as well as my own positive attitude, my children and friends. I am trying to be the best that I can be and I believe that when one door closes another door opens! I feel in control of the Parkinson's not the other way around. I believe that I am responsible for my own health and wellbeing. ***It is up to me!***

## 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.

## A New Friend



*When I meet a new friend...*

*There are things to share and things to explain.*

*There are questions, raised eyebrows and worry lines.*

*There may be smiles, and coffee and cookies.*

*There may be secrets told, once the time has passed and judgement is gone.*

*But when I meet a new friend that has Parkinson disease, like I do...*

*There are experiences to share and nothing to explain.*

*There is understanding even though our masks don't come off.*

*There is laughter until we pee, and coffee and cookies.*

*There are no secrets, or judgement, just love and acceptance...*

*Because we don't have time.*

- Cathy Ritchot

If you have a creative writing piece you would like to share please speak with your Regional Client Services Coordinator.

## 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)

## What is Parkinson disease?

Parkinson disease (PD) is a progressive and chronic process. It mainly affects parts of the brain controlling movement. Cells in the brain (in a place called the substantia nigra) produce an important chemical called dopamine. When a person moves, dopamine is involved in producing movements that are smooth and coordinated. Many people have symptoms between the ages of 50 and 60 years, but some have symptoms at a much younger age, others at a much older age. Over time, symptoms will get worse and may change to include more/different symptoms than when first diagnosed. This usually happens slowly, over years. As symptoms start to interfere with how one is able to do everyday things, there are treatments that can help.

### What causes Parkinson disease?

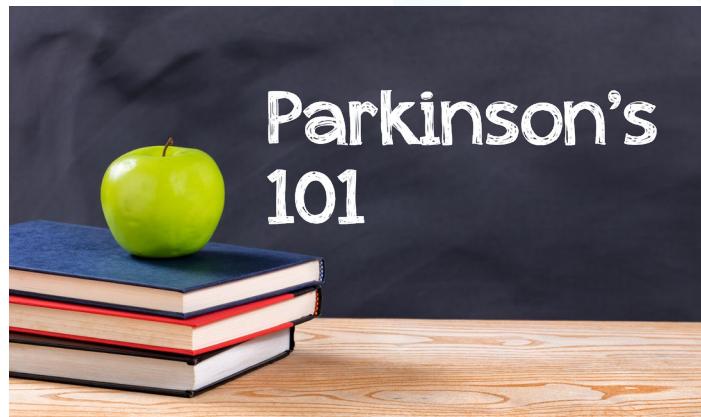
For reasons that we don't yet understand, the cells that produce dopamine start to not function properly. They don't make enough dopamine for movements to happen the way they did when there was enough dopamine in the system. To date, no one knows exactly how or why PD starts. Many researchers are trying to find the answers; and as it stands it looks as if aging, things in the environment (toxins or poisons) and abnormalities in some genes may trigger the changes in the body that lead to Parkinson disease.

### How is Parkinson disease diagnosed?

A doctor, often a neurologist or family doctor, will take a medical history and conduct an examination. They will make the diagnosis based on what they see and on the information provided to them. There is no blood test or laboratory exam that diagnoses PD. An MRI or CT scan may be ordered so the doctor knows that nothing else is going on (tumor, small stroke or other things). Medication is typically started when symptoms interfere with what you want to do.

### What does Parkinson disease look like?

Initially, most people will notice changes on one side of the body. It may be a tremor when an arm or leg is resting, doing nothing; it might be handwriting getting smaller; it may be a feeling of slowing down; one's face may lose some of its expression looking bored or depressed, even if the person is not; or footsteps get smaller. These are just a few common things people notice before they know about Parkinson disease. Everyone is different and changes are unique to every individual. Remember



– how PD looks on one person will not be identical to someone else with PD.

There are four main (motor) symptoms that a doctor will look for in making a diagnosis of Parkinson disease:

- **Tremor** – a trembling or shaking that is involuntary and usually seen in the hands or the legs when they are just resting. (Not everyone with tremor has PD and not everyone who has PD has a tremor.)

- **Slow movements (bradykinesia)** – describes when you want to move, everything is slowed down and it takes more of an effort to move.

- **Rigidity** – stiffness of muscles, usually detected by your doctor or health care team.

- **Difficulties with walking and balance** - footsteps get smaller; you may have a slight limp.

There are many other symptoms that people with PD may experience (though not always nor all of them) as time goes on. These are typically referred to as non-motor symptoms and can include: constipation, changes in speech and swallowing, fatigue, mood changes, sleep disturbances, and memory and thinking changes.

While there is not yet a cure for PD, there are many options available to help individuals and families live life to the fullest.

# NEWS

+ updates

## Annual General Meeting

Saturday, May 26, 2018

CALGARY

Membership is required to vote

If you will not be attending Hope Conference, but plan  
on attending the AGM please **RSVP no later than 2PM**  
**on Wednesday, May 23.**

To RSVP please call toll-free 1-800-561-1911 or email [info@parkinsonalberta.ca](mailto:info@parkinsonalberta.ca)

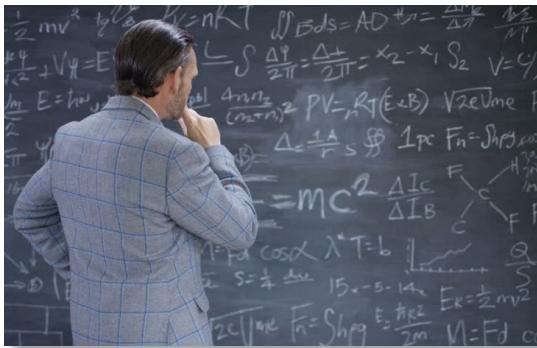
## APRIL is Parkinson Awareness Month

**Did you know** that worldwide it is estimated that **four to six million people suffer from Parkinson disease?** Did you know that over 10,000 of those live right here in Alberta?

While we all know that Parkinson disease isn't just an April occurrence; the spotlight does shine a little brighter during this month and can be a great opportunity to increase awareness and make an impact that can be felt year-round.

**Here are some ways that YOU can get involved!**

- **Get your place of work involved:** donate a portion of sales, have employees donate money to dress down or volunteer as a group to help with our tulip campaign
- **Host a fundraiser:** Porridge, pancakes, popcorn or pizza for Parkinson's (or something that doesn't start with the letter "p"), undertake a bottle drive or garage sale
- **Get Social:** Will launch our hashtags, social media images and banners in March to help raise awareness and spark a discussion about Parkinson disease
- **Step Up:** Register now for our annual Flexxaire Parkinson Step'n Stride™ Walk!  
[www.parkinsonalberta.ca/stepnstride](http://www.parkinsonalberta.ca/stepnstride)



many industries, a version of “insider speak” is developed that, though familiar to those in the know, can be like a foreign language to those who do not know. The following pages contain some of the more common terms and jargon used in regards to Parkinson disease.

**Akinesia** – the loss of the ability to move one’s muscles voluntarily. The absence of movement. Muscle rigidity.

**Apathy** – lack of interest, enthusiasm, or concern. A non-motor symptom of Parkinson disease that can appear as part of depression or on its own; and is likely due (at least in part) to a lack of dopamine.

**Ataxia** – a movement disorder marked by loss of balance and decreased muscle coordination during voluntary movements.

**Autonomic dysfunction** – problems with one’s autonomic nervous system (ANS). The ANS is made up of nerves that control several basic bodily functions including (but not limited to) blood pressure, heart rate, sweating, dry mouth, drooling, digestion of food and constipation.

**Bilateral** – affecting both sides

**Blood-brain barrier** – a naturally occurring barrier created by brain capillaries that prevents many substances from leaving the blood and crossing the capillary walls into the brain tissues.

**Bradykinesia** – slowness of movement

**Clinical Trials** – a clinical trial is any organized research study that uses human participants to test one or more health-related interventions (ie: drugs, surgery, etc) to evaluate the effects on health outcomes.

**Cognition** – the mental process involved in gaining knowledge and comprehension. These mental process include: thinking, knowing, remembering, judging and problem-solving.

## What Does It Mean? PARKINSON'S TERMINOLOGY AND JARGON EXPLAINED

Did you know statistics indicate that almost half of all patients do not understand medical language and/or jargon? It is not always an easy task to communicate complex information in a clear and manageable way given the needs of people are as varied as their levels of understanding about a disease and/or their health in general. This is not just a healthcare issue. For

**CP** – Care Partner

**Deep Brain Stimulation (DBS)** – a surgical option (wherein electrodes are implanted in a precisely targeted area of the brain) available to some individuals with PD whose medications alone are not enough to control PD symptoms and/or when extreme motor fluctuations impede optimum functioning.

**Dopamine** – a chemical produced by the brain responsible for relaying messages that plan and control body movement.

**Dopaminergic** – an adjective used to describe a chemical, a drug, or a drug effect related to dopamine.

**Duodopa** – a procedure encompassing both the pharmacologic and surgical component of PD treatment that sees the delivery of levodopa/carbidopa done in gel form via a tube and pump system directly into the body.

**Dysarthria** – speech difficulties due to impairment of the muscles associated with speech that can happen at any time and tend to increase as Parkinson’s progresses.

**Dyskinesia** – abnormal, uncontrolled, involuntary movement that can affect one body part or the entire body. May appear as a side effect of long-term drug treatment in Parkinson's and may worsen in response to stress.

**Dysphasia** – difficulty speaking

**Facial Masking** – see Hypomimia

**Familial Parkinson Disease** – Parkinson disease that runs in families and is thought to have a primarily genetic cause. This type of Parkinson's accounts for less than 5% of PD cases worldwide.

**Freezing** – a sudden, but temporary, inability to move that often occurs when initiating movement (such as walking) and/or at a "boundary" such as a doorway. Most individuals experience episodes when "off" or are due for their next dose of medication.

**Hypomimia** – the reduced or loss of facial expression. So named because the condition gives an affected person a fixed, mask-like expression. Often called facial masking or Parkinson's Mask.

**Hypophonia** – reduced vocal loudness/ soft voice.

**Idiopathic** – adjective meaning "of unknown cause." The typical form of Parkinson disease is idiopathic Parkinson's.

**Levodopa** – drug, containing a form of the brain chemical dopamine, commonly used to treat Parkinson disease.

**Micrographia** – an acquired disorder (commonly associated with PD) in which hand writing presents as abnormally small and cramped or the progression to progressively smaller handwriting.

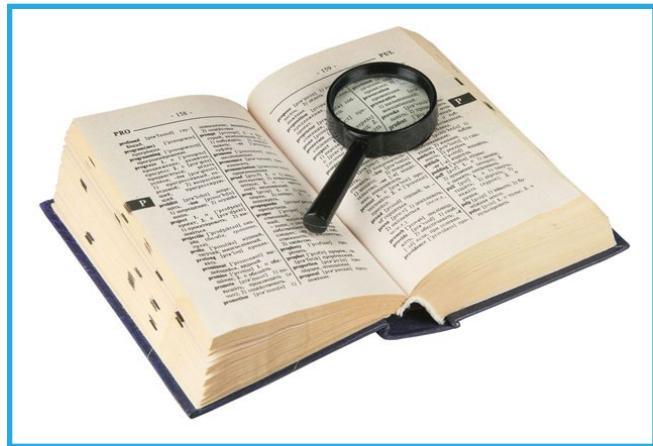
**Mild Cognitive Impairment** – characterized by executive function (multi-tasking, problem solving and reasoning) deficits, attention difficulties, visuospatial (depth perception, sense of direction) dysfunction, slowed thinking, difficulties in word-finding, and difficulties in learning and remembering information.

**Motor Symptoms** – symptoms that involve movement and mobility. In Parkinson's these include resting tremor, bradykinesia, rigidity and postural instability.

**Neuron** – a specialized cell that transmits nerve impulses; a nerve cell.

**Neurotransmitter** – a specialized chemical substance produced in nerve cells that permits the transmission of information between nerve cells. Dopamine is one example of a neurotransmitter.

**Non-Motor Symptoms** – symptoms that do not involve movement or mobility. In Parkinson's



the range of these types of symptoms is fairly large and includes sleep disturbances, mood disorders, psychosis, cognitive impairment and autonomic dysfunctions.

**Olfactory Dysfunction** – the reduced or loss of sense of smell.

**ON/OFF** – fluctuations that occur in response to levodopa treatment in which the person's mobility changes suddenly and unpredictably from a good response (on) to a poor response (off). "Off" is typically most noticeable as one's dose of levodopa wears off and before the next dose has been taken and/or takes effect.

**Postural Instability** – a tendency to fall or the inability to keep oneself from falling; imbalance.

**PWP/PWPP** – Person with Parkinson disease/Person with Parkinson Plus

**Range of Motion** – the full movement potential of a joint, usually its range in the ability to flex and extend.

**Resting Tremor** – a shaking that occurs in a relaxed limb, and disappears with active limb movements.

**Rigidity** – muscular stiffness; characterized by a resistance to movement in the limbs.

**Young Onset Parkinson Disease** – a form of Parkinson disease characterized by the onset of symptoms before age 50.



Parkinson disease affects the entire family. While it is, of course, true that only one person physically receives the diagnosis; the ripple effect created can have a tremendous impact on the care partner (and family).

## What do Care Partners (and Family Members) need to Know about Parkinson disease?

### Parkinson's is different for everyone

Like fingerprints or tiger stripes, the way a person diagnosed with Parkinson's experiences symptoms or progresses varies significantly from person to person. While there are common symptoms that many people with Parkinson's will experience, no two cases are the same. It is important not to compare your loved one to others you may know/meet with Parkinson disease. It is equally important to communicate with your loved one to gauge the ways they might be affected.

### Many of the symptoms are invisible

Many of the symptoms of Parkinson's are invisible. Signs of depression, fatigue and anxiety, for example, might not be immediately apparent, but your loved one may be suffering inside. It is important to encourage your loved one to be open and honest (in a respectful manner) about how they feel and the progression of their 'invisible' symptoms.

### Help your loved one maintain their independence for as long as safe and possible

As your loved one's Parkinson's progresses; their independence and/or options become more limited. If your loved one is able to perform certain activities, such as cooking meals, walking the dog or putting on a coat, then encourage him/her to do so even though it may take a little more time. It is also beneficial to talk about the future (finances, driving, living situations, etc.) early on and at periodic intervals to help maintain a feeling of independence and personal choice when options begin to become limited.

## Top 4 Tips for Care Partners

### 1. Work Together

Work with your loved one to maintain a care partnership. Caring within families should always be a two-way street — so that you and your loved one with Parkinson's are each able to give and receive support from the other, even when the Parkinson's becomes more disabling.

### 2. Get Support

Care partners (and families) do not need to face a Parkinson's diagnosis alone. Having a support system can give you a boost in meeting challenges and make you feel less alone in your role. Reach out to family, friends and the community for support. Seek help when/if you need it, and create a strong support network for your entire family.

### 3. Ask for Help

No one can read your mind, and most people don't want to risk offending you by suggesting you need help. The best strategy when asking for help is to be specific. Instead of saying to your relative, friend, or

neighbor, "I really need some help," try "I'd like to get out and do some errands on Tuesday – could you keep Alice company from 2-3 so I don't have to worry about leaving her alone?" Most people are happy to help when they know what you need.

### 4. Take Care of Yourself

Remember that your physical and emotional health is just as important as your loved ones'. The care partner role can be both demanding and draining at times, and we know that care partners tend to neglect their own health while caring for the other person.

Parkinson Association of Alberta's Client Services Coordinators are here to help care partners navigate their way through the ups and downs of caring for a loved one, maintain their sense of identity, and manage their own self-care through a variety of support options including support groups, supportive counselling and programs.

# 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 Tulip Campaign

This spring, Parkinson Association of Alberta is proud to present our annual Petals for Parkinson's Tulip campaign (formally Parkinson Alberta Grows) across the province. To celebrate the hope of the season, Parkinson Association of Alberta will once again be selling potted red parrot tulips for just \$8. Each tulip sold translates into more than \$5 for the organization. Sales will begin across the province in mid-March and continue on into early April – which is, of course, Parkinson Awareness Month!

If you are interested in volunteering to help at a sales location, by purchasing plants, or by helping us to expand our sales during the Petals for Parkinson's Campaign by helping us sell tulips to your friends, family and colleagues and social networks, please contact your regional office today.

### Save the Date for the 27th Annual Parkinson Tulip Tournament!

Tee off in support of Parkinson Association of Alberta on July 5, 2018 at Calgary's renowned Sirocco Golf Club! Day will include 18-holes of premier golf, barbecue lunch and chef-prepared dinner, entertainment, exciting on-course activities, auctions and more! Keep an eye on our website for more details as they become available.

### Save the Date for Flexxaire Step 'n Stride™ 2018!

**Step Up to Make a Difference for Parkinson's** at our 6th Annual Flexxaire Parkinson Step 'n Stride™ on September 8th & 9th! With nine Walks across the province, we are already busy planning to host the most exciting Flexxaire Parkinson Step'n Stride™ yet! Check out [www.parkinsonalberta.ca/stepnstride](http://www.parkinsonalberta.ca/stepnstride) for the latest news and updates and to find out more about the Step 'n Stride closest to you. Online registration is now open.

## PAST EVENTS

### Petals for Parkinson's Poinsettia Campaign

Parkinson Association of Alberta is excited to announce that our annual Petals for Parkinson's Poinsettia Campaign was a tremendous success this year! With the help of dozens of volunteers, businesses and friends of Parkinson Association of Alberta, the Campaign sold over 2500 mini poinsettias across the province and brought in over \$20,000 to help PAA continue to provide the best programs and services for Albertans living with Parkinson's in Alberta. Thank you to everyone who supported Petals for Parkinson's this winter!

### Grande Prairie's Purdy's for Parkinson's Campaign

Our annual Purdy's for Parkinson's Campaign in Grande Prairie had its most successful year yet in 2017! With the help of the exceptional volunteer team in the region, over \$2300 was raised from the sales of over \$8000 in Purdy's Chocolates! What a sweet way to give back!

# FUTURE → FORWARD

Connecting Communities through Wellness

## Hope Conference Returns this Spring!

Join us for the return of Alberta's largest Parkinson disease education event, Hope Conference for Parkinson's, to Calgary and Edmonton this spring!

SATURDAY, MAY 26, 2018

This year's conference will bring you face-to-face with leading experts, connect you to peers, and leave you feeling hopeful and energized!

Be educated and inspired by Hope Conference's two keynote speakers: **Dr. John Ratey** and **Nathan Dempsey**.

Dr. John Ratey is an Associate Clinical Professor of Psychiatry at Harvard Medical School, an internationally recognized expert in Neuropsychiatry, and a best-selling author.

Nathan Dempsey is a former NHL defenceman who was diagnosed with Parkinson disease at the age of 37. Nathan continues to play hockey, coaching and working at Edmonton's Vimy Ridge Hockey Academy.

Breakout sessions will be a part of the Conference, allowing attendees to personalize their conference experience. Attendees will choose two breakout sessions from the following options.

In Calgary, the session topics are: Advanced Care Planning, Music Therapy, PD Aging vs Natural Aging, and one other topic yet to be determined.

In Edmonton, the session topics are: Advanced Care Planning, Dance (interactive), Nutrition, PWR! (interactive), and one other topic yet to be determined.

Parkinson Association of Alberta's always popular Ask the Experts also returns to Hope Conference, giving

attendees the opportunity to ask their own questions and have them answered by a panel of experts in real time!

### 2018 Hope Conference Itinerary

7:30AM – 8:00AM – AGM Registration  
8:00AM – 9:00AM – Hope Conference Registration  
8:00AM – 9:00AM – AGM  
9:00AM – 9:15AM – Hope Conference Welcome  
9:15AM – 10:15AM – Keynote Speaker: **Nathan Dempsey**  
10:15AM – 10:30AM – Break  
10:30AM – 11:30AM – Keynote Speaker: **Dr. John Ratey**  
11:30AM – 11:45AM – Break  
11:45AM – 12:35PM – Ask the Experts Q&A Panel  
12:35PM – 1:15PM – Lunch  
1:15PM – 2:05PM – Breakout Session #1  
2:05PM – 2:20PM – Break  
2:20PM – 3:10PM – Breakout Session #2  
3:15PM – Closing Remarks

Parkinson Association of Alberta encourages you to take advantage of early registration pricing this year. Register between February 12 through May 7 to receive special conference pricing of \$35/Member and \$45/Non-Member.

Learn more about advances in Parkinson disease, discover new strategies for living well, and connect with friends old and new. You won't want to miss this informative and inspiring event!

For more detailed information on Hope Conference - including keynote speaker bios, breakout session descriptions and online registration visit our website at:  
[www.parkinsonalberta.ca/hopeconference](http://www.parkinsonalberta.ca/hopeconference)

# Become a CHAMPION OF HOPE



In the fight against Parkinson disease, research is vital; every minute spent, every breakthrough (big and small), every donation made fuels our power to beat it!

Parkinson Association of Alberta's mission is to make every day better for Albertans. Over the next four years, our goal is to raise \$5 million for the Champions of Hope Research Fund to help fund Parkinson research, and ultimately, to find a cure for Parkinson disease.

Parkinson Association of Alberta's is excited to launch a new and improved research component on our website ([www.parkinsonalberta.ca/research](http://www.parkinsonalberta.ca/research)) aimed at showcasing research in Alberta and the Champions of Hope (COH) Program. The five elements of the COH web pages are:



## Funded Research

Alberta is home to many talented researchers who are taking on Parkinson's disease from a variety of perspectives, all aimed at making a difference in the lives of people affected by Parkinson's. On this web page you will find out who some of Alberta's researchers are, meet the post-doctoral fellows and graduate students who are currently receiving funding and find out a little bit about what they are working on.

## Participate

The fight to end Parkinson's is a multifaceted one. Getting involved in research studies is one of the best ways to be a part of it! This web page features a listing of current research studies open for participation. It is important to note that many studies are open to both people with Parkinson disease AND their care partners/loved ones.



## Funding

In 2017, Parkinson Association of Alberta contributed \$200,000 to research by post-doctoral fellows and graduate students. To further medical research, the Champions of Hope program will look to fund innovative Parkinson's research projects.

## Give

Interested in channeling your inner Champion of Hope and donating to the program? On this page donors can select a specific area to support or provide an unspecified Champions of Hope grant. Please note that multi-year contribution plans are available and stock and asset contributions are also accepted.



## Champions

Every donor is important to Parkinson Association of Alberta, and we want to ensure that we acknowledge the people, companies, and funders accordingly. On this page you will meet our Champions.

# PARKINSON'S MEDICATIONS

If you have Parkinson disease (PD), you will eventually need to take medications. Medications can help manage or reduce symptoms like slowness, rigidity and tremor. It may not be necessary to immediately start drugs to treat PD symptoms just because you have them. When symptoms start to interfere with your quality of life or the ability to function at a level that you want (in other words, they are causing "disability"), 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 medication is one you make together with your doctor.



There are no medications that slow or stop the progression of PD. As Parkinson's progresses and your symptoms change, your medications will also need to change. This may be the kind of drugs you take, how many pills you take and the timing of each dose. It is important to keep your doctor and health care team aware of any changes in your PD symptoms. Adjustments in medications are aimed to help reduce your Parkinson's symptoms.

## **What Types of Medication are there and What Do They Do?**

Symptoms of PD appear when the levels of a chemical in your brain, called dopamine, are low. For reasons we don't understand, in PD the cells producing dopamine don't function properly. With too little dopamine, movements don't happen the way they did before. They are slower, there may be a tremor and coordination may be "off".

Drugs used in PD are primarily aimed to work on the dopamine system in the brain. They work mainly to improve problems with movement. Most drugs work in one of the following ways:

- increase the amount of dopamine in the brain
- stimulate parts of the brain influenced by dopamine
- prevent the breakdown of dopamine before it can be used in the brain

### **Levodopa**

Levodopa is the "gold standard" for treating PD symptoms. It is the most effective treatment for the motor symptoms of PD. It works by replacing the dopamine in the brain. Levodopa is always combined

with either carbidopa or benserazide which help the levodopa get into the brain where it is changed into dopamine. Levodopa may be used alone or in combination with other PD 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**)

If you experience nausea with levodopa, taking your pills with food can sometimes help to reduce feelings of sickness. Sometimes the nausea will go away after you get used to taking the drug. For some people, protein seems to interfere with the way levodopa works. The protein may affect how well the drug is absorbed by the body. If this is true for you, you may benefit from taking your medication 30 minutes before a meal.

### **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 PD symptoms or in combination with other PD drugs.

## Catechol-O-Methyltransferase (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.

## Monoamine-Oxidase-B (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.

## Levodopa/carbidopa Intestinal Gel (Duodopa)

Health Canada just approved this method of administering levodopa/carbidopa into the body. Instead of taking a pill, a tube is surgically placed into the small intestine. A pump attached to the tube then delivers the drug, in the form of a gel, into the small intestine. People with more advanced PD who are having trouble with managing PD symptoms and side effects with oral drugs may benefit from this form of drug delivery. Duodopa is currently available, in a limited fashion, in Edmonton and Calgary through the Movement Disorders Programs.

## 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.

## Anticholinergics

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**)
- benzotropine (**Cogentin**)

Your medications are tailored to treat you and your symptoms. Do not try someone else's regime – it has been tailored for them! It is critical to take the medication(s) exactly as the doctor has prescribed them. If you are concerned about the medications you are taking, do not change them without talking with your doctor or health care team. Some drugs need to be stopped slowly to avoid serious complications. All medications have potential side effects. Your doctor should review the most common ones before you start a new medication. Contact the doctor who prescribed your drugs if you have side effects that concern you.

## On Time...Every Time

People are often very sensitive to the timing of medication. A delayed or missed dose may have a negative impact on the effectiveness of the medication. People may have difficulty getting good symptom control back after a delayed or missed dose of medication. It may take hours or days to get back into their normal response to the medication. Some people find a timer or an alarm on a cell phone a helpful reminder to take pills.





### HOST A Third Party FUNDRAISER!

Every year Parkinson Association of Alberta (PAA) runs several different events across the province with the goal of raising funds to support our mission to make each day better for Albertans living with Parkinson's. Our events range from our Petals for Parkinson's Campaign to our largest fundraiser, Flexxaire Parkinson Step 'n Stride™ and a host of other events in-between. We would love to be able to run galas, and breakfast events, bike races and hockey tournaments but at the end of the day, we have to focus our efforts on running just a few key events every year to make the most of our budget and staffing.

If you've ever seen an event advertised and thought, "I wish Parkinson Association of Alberta would do an event like that", well guess what? With your help, we can!

If you have an idea and want to create your own event in support of Parkinson Association of Alberta, we are happy to help! Here is a look at just a few ways that clients around the province have stepped up in support of Parkinson Association of Alberta:

**Tour de Eddy:** In honor of his Dad Eddy, this summer, Brent Jossy and his wife Leah have rounded up ten of their family members to ride their bikes in the Tour de Eddy from Kimberley, BC to Josephberg, AB. Parkinson Association of Alberta is assisting by providing a pledge site for the family so that they can help to solicit donations for the Tour! Watch our social media channels this summer as we cheer on the Tour de Eddy!

**Garage Sales:** For many years, our Medicine Hat Support Group has gathered all their unwanted items and held a huge local garage sale in the community.

# SUPPORT GROUPS

While many of our Support Groups run monthly, September through June. Please check your Regional section of our website for the most up-to-date information.

<b>ALBERTA</b>		<b>1-800-561-1911</b>
<b>ARTA CHARITABLE FOUNDATION'S TELE-SUPPORT GROUPS – BEGINNING MARCH 2018!!!</b>		
3 <sup>rd</sup> Wednesday - <b>Care Partners</b>	6:30 pm – 7:30 pm	
3 <sup>rd</sup> Thursday	10:00am – 11:00am	Advance registration is required to receive call-in instructions & a passcode; call the above number.
4 <sup>th</sup> Thursday - <b>Parkinson Plus</b>	10:00am – 11:00am	
<b>CALGARY REGION</b>		<b>403-243-9901</b>
<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
<b>EDMONTON REGION</b>		<b>780-425-6400</b>
<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
Feb 15 & Apr 11 - <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



# AT A GLANCE

WESTLOCK		
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>
GRANDE PRAIRIE		
2 <sup>nd</sup> Tuesday of the month	3:00 pm – 4:30 pm	<b>Wildrose Manor</b> – 9358 – 70th Ave
<b>LETHBRIDGE REGION</b>		<b>403-317-7710</b>
LETHBRIDGE		
3 <sup>rd</sup> Thursday of the month	2:00 pm – 3:30 pm	<b>Lethbridge Senior Citizens Org.</b> – 500 – 11th St S
TABER		
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>
LLOYDMINSTER		
4 <sup>th</sup> Tuesday of the month	2:00 pm – 4:00 pm	<b>Southridge Community Church</b> – 5701 – 41 Street
WAINWRIGHT		
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>
MEDICINE HAT		
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>
CASTOR		
Mar 27 & May 29	1:30 pm – 3:30 pm	<b>Paintearth Lodge</b> – 4501 – 55 Ave
LACOMBE		
4 <sup>th</sup> Wednesday of the month	10:00 am – 12:00 pm	<b>Wolf Creek Community Church</b> – 4110 Hwy 12
OLDS		
2 <sup>nd</sup> Wednesday of the month	1:30 pm – 3:30 pm	<b>Sunrise Village</b> – 5600 Sunrise Cres
RED DEER		
3 <sup>rd</sup> Wednesday of the month	10:30 am – 12:30 pm	<b>Davenport Church of Christ</b> – 68 Donlevy St
THREE HILLS		
Apr 4 & Jun 6	1:30 pm – 3:30 pm	<b>Community Drop In Centre</b>





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: \_\_\_\_\_



## PARKINSON ASSOCIATION OF ALBERTA

# What We Do to Help You Live Well with Parkinson Disease and Parkinson Plus Syndromes

**T**he impact of Parkinson disease is multidimensional and ever changing, affecting not only the individual diagnosed, but also their loved ones as well.

For over 40 years, Parkinson Association of Alberta has been the only charitable organization dedicated to improving the wellbeing and day-to-day lives of Albertans living with and affected by Parkinson disease and Parkinson Plus Syndromes. Parkinson Association of Alberta provides no cost specialized “core” support services, education, referrals, information and resources and low-cost programming to those living with Parkinson disease, Parkinson Plus Syndromes, their families and care partners. The aim is to help individuals and families adjust to the reality of Parkinson’s, identify and implement goals and actions that will manage symptoms, and improve quality of life.

### **Parkinson Association of Alberta's core services include:**

- **One-on-One/Family Supportive Counselling** is a valuable tool to help people with Parkinson’s, their loved one(s) and/or other family members and friends deal with Parkinson’s in a positive, constructive manner. It is a confidential and safe place to ask questions, talk about stresses and concerns, establish goals and create action plans to live life to its fullest with Parkinson’s. Parkinson Association of Alberta is pleased to offer this service both in-person (office and/or home visits) and over the phone either by directly calling a Regional Office or via PAA’s toll-free PD Helpline (1-877-243-9992).
- **Support Groups** are a great way to learn about Parkinson’s, share experiences, develop better coping skills, and feel less isolated as attendees make connections with others facing similar challenges. Parkinson Association of Alberta is pleased to offer 36 Support Groups in both traditional in-person forums as well as telephone call-in groups!
- **Information and Resources** are a fundamental component to ensuring individuals and families are getting the right facts, tools and information about Parkinson disease and Parkinson Plus Syndromes whether they are at the beginning of a Parkinson journey, or have been travelling the path for many years. Information and resources (including printed information/resources and Aware in Care kits) can be accessed by calling a Regional Office or visiting [www.parkinsonalberta.ca](http://www.parkinsonalberta.ca).
- **Education** contributes to health and well-being by equipping people with knowledge and skills for problem solving, helps provide a sense of control and mastery over life circumstances, and improves people’s ability to access and understand information to help keep them healthy. Parkinson Association of Alberta offers speaker series in many Regions across the province as well as providing video access to past speakers via our YouTube Channel at [www.youtube.com/user/ParkinsonAlberta](https://www.youtube.com/user/ParkinsonAlberta).

Parkinson Association of Alberta also offers a variety of programming (physical, voice/speech, cognitive and social) options across the province - speak to a Regional Client Services Coordinator to find out what is available in your Region. And, with an eye on hope and a brighter future, Parkinson Association of Alberta also aims to innovate and inspire by committing crucial funds for research via the Champions of Hope program.

# FUTURE → FORWARD

Connecting Communities through Wellness

May 26, 2018

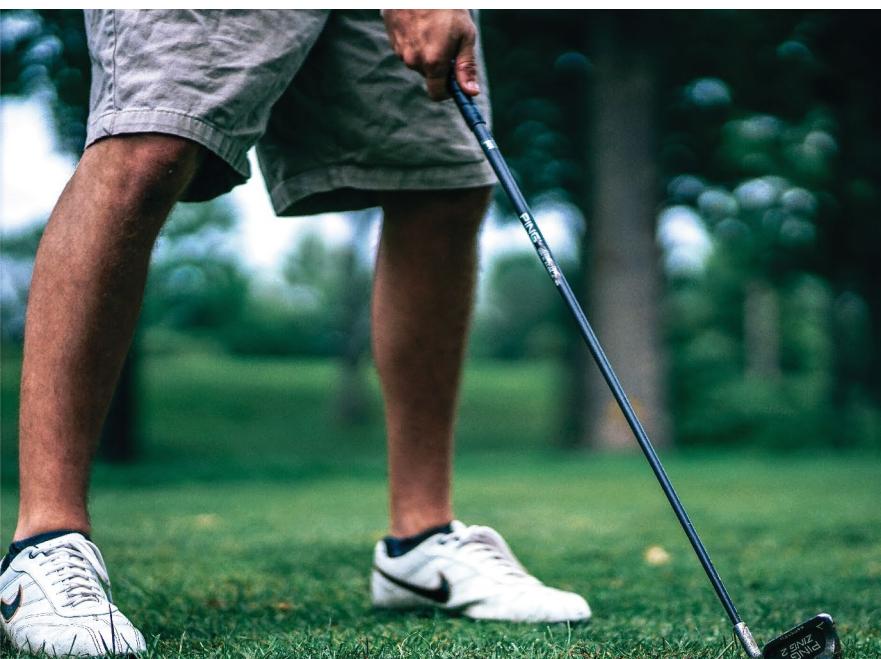
Calgary ~ Edmonton



*Hope blooms  
this spring*

\$8  
/pot

Talk to your Regional Coordinator  
or visit our website at  
[www.parkinsonalberta.ca/tulipcampaign](http://www.parkinsonalberta.ca/tulipcampaign)



## SAVE THE DATE

**27th Annual Parkinson  
Tulip Tournament**

*Tee off 'fore' a good cause*

July 5, 2018

**Online registration will open soon!**

# APRIL is Parkinson's Awareness Month

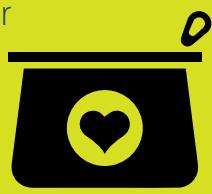


Parkinson disease is the **second most common** neurodegenerative disorder after Alzheimer's disease.



Introduced in 1967, **Levodopa** is considered the **"gold standard"** for treating motor symptoms in Parkinson's.

PAA has **Aware in Care kits** available to help **prepare and empower people with PD**. Each kit includes tools and info to help in the case of a planned or emergency hospital stay.



**Research** in Parkinson disease is delving into a many aspects: **physical, cognitive & emotional aspects** as well as **a cause** and, of course, **a cure**.



PAA provides no cost specialized support services, referrals, education, information & resources and low-cost programs to those living with Parkinson's, their families and care partners.

PAA's **Champions of Hope** Research Program aims to **raise \$5 million** to help fund research, and ultimately, to find a cure for PD.



PAA's Client Services Coordinators provide one-on-one & family supportive counselling via **telephone, PD Helpline, and in-person** at our **offices** or **home visits**.



PAA runs **36 Support Groups** across Alberta including **3** done via telephone at our **Tele-Support Groups**.