# Parkinson PULSE Connecting people living with Parkinson disease in Alberta

### ON THE WAY DOWN...

Swallowing & Oral Health Issues in Parkinson Disease



# Peer-to-Peer Program NOW RECRUITING MENTORS AND MENTEES

Charitable FOUNDATION

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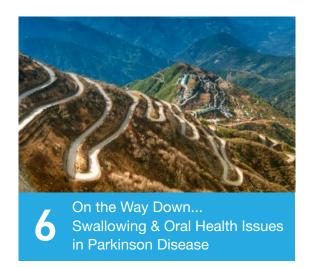




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Articles and information contained in the Parkinson Pulse are provided solely for the readers' interest. Articles do not necessarily reflect the views of Parkinson Association of Alberta and are NOT intended as medical advice. Please consult your doctor 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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We welcome your comments, suggestions and questions. Email us at **communications@parkinsonassociation.ca**; or call us toll-free at **1-800-561-1911.** 



#### From the Desk of

### THE CEO



Parkinson Association of Alberta prides itself on delivering quality, professional and personalized support and services to all Albertans with Parkinson disease and Parkinson's Plus Syndromes, their families and care partners.

It can be hard to look ahead to potential challenges on the horizon. It can be difficult to

strike a balance between knowing and not knowing, living life for today and planning for the future, being hopeful and feeling hopeless. On one hand too much information and planning can lead to stress and frustration as there really is no way to plan for all the things that may or may not happen. On the other hand there is little to be gained from doing the proverbial ostrich-head-in-the-sand move. Ignorance really isn't that blissful in the long run. In fact, the longer you wait to address a situation or any pain or discomfort you may be experiencing, the worse it is likely to get.

So what then, is the balance? The balance is inherent in the choices we make. There is hope in those choices, in preparation and in doing the best you can to live for today while planning for tomorrow.

This issue takes on an often overlooked aspect of Parkinson disease – swallowing and oral health issues (page 06). These issues are often overlooked because it is a part of those bodily functions that so many of us simply take for granted. However, once you take a deeper dive into the complexities of the processes when associated with Parkinson disease – dysphagia (page 07), bruxism (page 08) and even how to maintain good oral hygiene (page 12), you begin to get a clearer picture

of what is at stake and what can be done about it. And there is hope in that as well.

Speaking of hope, I would be remiss if I didn't take one last opportunity to encourage you to participate in the upcoming 2019 Hope Conference (page 14).

This year's Hope Conference has transitioned back to a PROVINCIAL conference based on your feedback! The last provincial Hope Conference we held was back in 2014. This is such an exciting opportunity not only to be educated and inspired by internationally renowned inspirational and research speakers (John Baumann and Dr. Ron Postuma, respectively), but to gather together as a large, strong and impactful Alberta Parkinson's Community! The Hope Conference Committee has gathered six healthcare professionals with extensive knowledge in Parkinson disease to present breakout sessions. Many of these experts will join Dr. Oksana Suchowersky on the always popular Ask the Experts O&A Panel.

On the fund development front there is a lot going on as well. Staff have wrapped up many of our inaugural Tap'd Out events and have started preparations for not one, but TWO upcoming golf tournaments and of course, the 7th annual Flexxaire Parkinson Step 'n Stride™. You can find information regarding these and other events on our website.

John Petryshen

CEO, Parkinson Association of Alberta



#### **Community and Connections**

Bev & Blair Gordon



ev and Blair Gordon have been involved in Real Estate in the Foothills area since 1977 and will be celebrating the 15th Anniversary of their relationship with Century 21 this year. They have always been supportive of their team and the community and have been instrumental in creating an amazing culture that mirrors their business and personal philosophies. As long-time residents in High River and area they continue to find ways to involve their family and their team to create and enhance an amazing culture at Century 21 Foothills.

Their latest pillar within their Gordon Family Initiative is the partnership with the Parkinson Association of Alberta. This is a special relationship where amazing friendships and partnerships have been developed. With the development of their family initiative, there was an instant bond and since then they have committed to working with events such as the Venue

and a commitment to Performing Arts and Culture in the community while creating an atmosphere to fundraise and support their goals.

Family is key... their youngest daughter Trisha and Darren and their family live in High River. Darren is a critical piece of the family business, working with Century 21 and Blair and Bev, since the inception. The two granddaughters, Annie and Maddie are a growing concern and continually support and participate in their charitable events and causes...passing the torch. The oldest daughter, Tiffany has become more involved with the family business after managing and running a golf course operation and is now involved with promotion, development and engagement when it comes to community initiatives.

The entire team at Century 21 Foothills gets behind and promotes and endorses their charitable and creative ventures. Each individual team member, if asked, would reiterate what a value they bring to the community. According to their family, they feel that their parents are both very committed to the community and community initiatives, and have instilled these qualities within them. Their vision is to create a team atmosphere which is based on meaningful partnerships, friendships, trust, community and culture. Their associates grow with the business and feels like a part of a family, which in turn they continue to promote and encourage it with their actions.



#### **CLIENT SERVICES CORNER**

# Parkinson's in Northern Alberta

Written by: Shauna Livesey

ello, my name is Shauna Livesey and I am the Client Services Coordinator for the Grande Prairie and Northwestern Region. My background is in Social Work. A lot of my region covers northern areas so I want to take this time to talk about those specific communities and the impact this has on those living with and affected by Parkinson disease (PD). For those that have never been to Grande Prairie, our population is 63,166 in the city proper. The people the Grande Prairie municipality serves however is closer to 150,000.

When reaching out for and/or accessing services it can be difficult when one lives in northern communities; especially for a disease that is as complex as Parkinson's. Specialized medical professionals, programs and services are either limited or unavailable unless one travels sometimes one to five hours away, if not further. Travelling expenses and the stress of travel are a burden for many. There is also the isolation that can come with living in an area of the province that is more remote.

Recently, I posed a question to our Grande Prairie Support Group...

#### "What do you think/feel the barriers to living in and around Grande Prairie are?"

The answers were not surprising and were very much the same as noted above. Without direct access to neurologists in the region, many find themselves having to travel to Edmonton or Calgary to see their neurologists. Many clients expressed that they would like to have a movement disorder clinic or a specialty Parkinson's clinic. Generally, people in Grande Prairie and outlying northern communities are travelling to Edmonton for this. Although a wonderful clinic with nothing but positive reviews, the financial burden and the toll travelling can take on a person with Parkinson's can at times be too much. A neurologist and other services would be beneficial given the amount of people who travel for appointments each year.

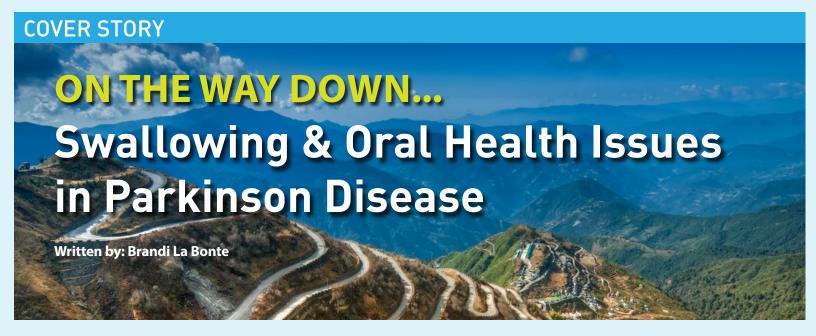


Another point our clients noted was that for some travelling to see a neurologist isn't a viable option, so they rely on their local family doctors. It should be noted that many people with Parkinson disease see only their family physicians, and they receive wonderful care and support. The hope from the clients was that there might be a way to help make the medical community in the north as a whole more aware of PD diagnosis, symptoms, resources and information. This is why we go out and do presentations and host information sessions. And why we need our community members to speak out about Parkinson's and educate whoever you can, whenever you can!

While our communities are vibrant and supportive, it can be isolating at times to live in a northern community, especially when living with Parkinson's and combating those types of feelings on an almost daily basis.

The good news is Parkinson Association of Alberta has a number of options to help people feel not only supported, but less isolated. As we know, support groups allow a person to feel connected and give a sense of community; but with the vast distances between communities in the north attending a group in person isn't always an option. This is why we have created our Tele-Support Groups which are telephone call-in groups available to anyone province wide. We also offer a toll-free PD Helpline that gives people access to a trained Client Services Coordinator who can help provide information, support and resources.

Living in northern areas of Alberta is not all doom and gloom. We get to enjoy the beauty of nature right out our back door AND this community knows how to come together for not only their close loved ones but others in the community as well. Grande Prairie sometimes gets the name of being a rough and tough oil and gas town, but that could not be further than the truth.



The human body is a machine consisting of many different, interconnected machines. Each machine (heart, lungs, intestines, etc.) runs at its own individual speed, but all function in a specific, predetermined relationship to each other. In this sense, the body is similar to the most complicated man-made machines, such as automobiles or rocket ships, which consist of many separately functioning components that are mechanically linked together, each of which, in itself, is a complete machine. In fact, the body is the most complex of all such compound machines.

The trouble is unlike our automobiles (and I'm sure rocket ships) wherein most of us pay attention to items like fuel gauges, oil changes, tire rotations to ensure our vehicle is running optimally; we often do not pay attention to what is going on in our own internal systems.

Take the simple act of eating and drinking. Odds are you probably do not think about what is happening with your teeth, mouth and throat to help get that food and drink down into your stomach. Swallowing is such a natural occurrence, that we often take it for granted. We assume that our body's swallowing mechanism will work and do what it is supposed to do to provide our body with the sustenance it requires.

For people with Parkinson disease and Parkinson's Plus Syndromes, this simple act is not something that can be taken for granted. In fact, more than 80% of people with Parkinson's will experience difficulties with this process. Swallowing difficulties and oral health issues can occur at any stage of Parkinson disease; and, because of the progressive nature of Parkinson's, these issues (particularly swallowing difficulties) can continue to change over time. The good news is early intervention and treatment can help ensure optimum health, safety and quality of life.

First and foremost, ensuring you are receiving the best possible nutrition to fuel your "machine" is essential. Fuelling your machine with over-processed foods is tantamount to putting cheap, inferior fuel in your vehicle. It may do the job initially, but in the long run will affect the overall performance, reliability and longevity.

While there is no singular diet that can treat, slow progression or cure Parkinson disease; there are things you can eat and/or drink to improve general wellbeing and tackle some non-motor symptoms and other issues in Parkinson's.

- Staying hydrated and eating fibre-rich foods can help alleviate constipation and/or low blood pressure.
- Limiting sugar, caffeine and alcohol (particularly before bed) can improve sleep.
- Diet and Parkinson's medications can often impact each other – ie: some medications work best on an empty stomach, while others benefit from being taken with food. For some taking their Parkinson's medications with or close to a protein-heavy meal can affect absorption. This doesn't mean protein should be avoided, just that timing may need to be altered. Work with your doctor to find the right option for you!

Throughout this issue we will take a look at some specific issues with swallowing and oral health in Parkinson disease including: Dysphagia, Bruxism, Dry Mouth, Drooling, and practicing Good Oral Hygiene.

It is our hope that you find this (and other issues) informative, beneficial and helpful. We welcome your comments, feedback and suggestions at

communications@parkinsonassociation.ca

# Dysphagia

Written by: Brandi La Bonte

ysphagia (not to be confused with dysphasia) is defined as "difficulty or discomfort in swallowing". In layman's terms it means it takes more time and effort for the body to move food and/or liquid from one's mouth to their stomach. More than 80% of people with Parkinson disease develop dysphagia during the course of their disease<sup>1</sup>.

Swallowing is a vital function of the body; and problems with that function such as malnutrition, choking and/or inhalation of saliva, foods or fluids into the lungs, which can lead to aspiration pneumonia; can be injurious or even fatal. It is essential to speak with one's treating physician if issues with swallowing are experienced. Treatment of dysphagia may include rehabilitative undertakings, modifications to diet, adjustments to personal behaviors, or some combination thereof.

In terms of diet, modifications to the texture of food may be implemented to allow for safe intake. In terms of rehabilitative and adjustments to personal behaviors, a doctor may refer to a Speech Language Pathologist (SLP) who is a specialist in dysphagia and other speech and swallowing issues. The Speech Language Pathologist will discuss strategies, options and exercises that may help improve swallowing issues.

Therapies designed to improve swallowing are focused on strengthening muscles and building coordination of the nerves and muscles involved in swallowing. With the direction of a Speech Language Pathologist, the following are examples of exercises that may assist in strengthening and increasing movement of the muscles in the face and throat, which in turn will help make food intake and swallowing safer and easier.

#### Shaker Exercise2

Helps strengthen muscles and improve ability to swallow

**How to Perform:** First, lie flat on your back and raise your head slightly off the ground. Have your head raised high enough so that your eyes are fixated on your toes. Hold this position for a few seconds and then place your head back down. Repeat this same movement a few more times. For best results, do this exercise three to six times throughout



the day. Over time, you can increase the duration of the head lift and the number of repetitions.

#### Hyoid Lift Maneuver<sup>2</sup>

Helps build swallowing muscle strength and control

**How to Perform:** Place multiple small pieces of paper on a towel in front of you. Next, place a straw in your mouth and suck on the straw, allowing the paper to get picked up by the tip of the straw. Keep sucking on the straw as you carry the straw over to a cup, and stop sucking to release the paper into the cup. You should aim to successfully place all of the pieces of paper into the cup. You can start out with just 3 to 5 pieces of paper and slowly increase to around 10.

#### Tongue Strengthening Exercise3

Helps improve the contact and coordination between the different muscles used while swallowing

**How to Perform:** Stick out your tongue as far as you can. Put something flat like a spoon or tongue depressor on your tongue. Push against your tongue with the flat object, and push your tongue against the object. Hold for a couple of seconds. Repeat 5 times.

#### **References:**

- **1** Suttrup, I, Warnecke, T. (2016) Dysphagia in Parkinson's Disease. 31: 24. https://doi.org/10.1007/s00455-015-9671-9
- **2** Murphy, L, NAPA. (2018). 5 Easy Swallow Strengthening Exercise for Dysphagia https://www.napacenter.org/swallow-strengthening-exercises/
- **3** Johns Hopkins Medicine Health Library. Swallowing Exercises: How to Do Tongue-Strengthening Exercises. https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/swallowing-exercises-how-to-do-tonguestrengthening-exercises



# Bruxism

Written by: Brandi La Bonte

Bruxism is involuntarily oral activity that includes the clenching or grinding of teeth that can occur in a sleep or awake state. Bruxism has been reported in Parkinson disease as well as in other Parkinsonian syndromes, such as MSA, and also in relation to levodopa treatment<sup>1</sup>.

Symptoms of bruxism may include (it should be noted that most of the time bruxism is not severe enough to cause major problems):

Facial pain

**Earaches** 

noise from the grinding or clenching that wakes a person and/or their sleeping partner

Teeth that are oversensitive to cold, heat, or pressure

Receding gums

Temporomandibular joint (TMJ)
disorders

Headaches—tension headaches from day grinding and morning headaches for nighttime bruxism

Jaw damage

Depression

Chewed places on the tongue or cheek

Damage to teeth: chips fractures, worn enamel, flattened tops, loose teeth

Speech and swallowing difficulties

In relation to Parkinson's, the rigidity and spasms of the disease itself can affect the muscles of the jaw, causing the jaw to clamp shut. This, in turn, puts tremendous force on the teeth and can cause them to wear down over time or even break. This can also interfere with eating, drinking, and speaking when it prevents the mouth from opening. Bruxism, as with many Parkinson's symptoms, tends to lessen or disappear during an "on" period and worsen or return during an "off" period.

Treatment options vary and depend on the severity of the bruxism, be sure to discuss with your treating physician to determine the best course of treatment.

#### Self Care

Drink water

Manage stress

Try self-massage on the face and jaw

Apply ice or damp heat to a sore jaw

Avoid caffeine, alcohol and smoking as they can increase bruxism

Schedule regular dental visits so a dentist can monitor damage

Mouthguards and splits can be worn to protect teeth and keep the jaw in a more relaxed position. In terms of medications, muscle relaxants (antispasmodic drugs) or anticholinergic medications sometimes provide relief, although they can have undesired side effects such as drowsiness and, with anticholinergics, dry mouth. When bruxism is so severe that it prevents opening the mouth and chewing, Botulinum toxin therapy is often effective for immediate and long-term relief. These injections paralyze small segments of the muscles, causing them to relax.

#### **References:**

1 Yair Zlotnik, Yacov Balash, Amos D. Korczyn, Nir Giladi, and Tanya Gurevich, "Disorders of the Oral Cavity in Parkinson's Disease and Parkinsonian Syndromes," Parkinson's Disease, vol. 2015, Article ID 379482, 6 pages, 2015. https://doi.org/10.1155/2015/379482.

# EVENTS + updates

#### **UPCOMING EVENTS**

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

#### **A Diamond Evening**

Friday, May 24 Esplanade Arts and Heritage Centre - 401 1 St SE, Medicine Hat

Tickets are \$60 each

For tickets and more information check out our website **parkinsonassociation.ca/adiamondevening** 

## 28<sup>™</sup> Annual Parkinson Tulip Golf Tournament

Thursday, July 4 at Silver Springs Golf Club – Calgary This year promises to be a fantastic tournament with new activities on the holes and more!

To register go to our website **parkinsonassociation. ca/tuliptournament** or call 1-800-561-1911

#### Parkinson's Perk Coffee

Available across the province – Perk Up for Parkinson's! \$20/1 lb bag

Contact your local representative for more information or call 1-800-561-1911

#### Flexxaire Parkinson Step 'n Stride™ 2019

Nine walks across the province taking place on September 7 & 8! To stay up-to-date check out our website at **parkinsonassociation.ca/stepnstride** or follow us on social media!

Online registration is open! Register as an individual or team today!

#### NEW - 15<sup>TH</sup> Annual Mark Mercier Shanker Golf Tournament

Monday, September 9 at Windermere Golf and Country Club - Edmonton

We are partnering with the Mark Mercier Foundation on this golf tournament in Edmonton.

To register go to our website **parkinsonassociation. ca/markmerciergolftournament** or call 1-800-561-1911

#### **PAST EVENTS**

### Tap'd Out Food + Beverage Festival 2019

We had a full house at both Tap'd Out events with 85 – 100 people at each event. Funds raised was over \$8,000!

# Would you like to get involved in PAA?

#### **A Diamond Evening**

Parkinson Association of Alberta would like to thank Blair, Bev and Tiffany in their support for our first ever Diamond Evening concert tribute to Neil Diamond that took place on Friday, May 10. Not only did the three of them contribute as a cash sponsor for the event at the Sweet Caroline sponsorship level but they also hosted and spear-headed the Diamond Evening committee.

We are currently looking for volunteers to join various event committees, event day preparations, office support, program support and more! Call us at 1-800-561-1911 or email info@parkinsonassociation.ca for more information and how you can get involved!

# Dry Mouth

Written by: Brandi La Bonte

Xerostomia or dry mouth is a non-motor symptom of Parkinson disease and can be exacerbated by the medications (particularly anticholinergics) used to treat it. Dry mouth is a frequent but often unreported symptom and may be an early manifestation of autonomic involvement in Parkinson disease.

Dry mouth in the simplest of terms is a condition that results in deceased saliva production. Saliva is not only necessary, but important in maintaining good oral health, and assisting with the breakdown of food, swallowing and speech.

People with Parkinson's can experience varying degrees of dry mouth which can contribute to cavities, gingivitis, periodontal disease and mouth infections (ie: oral thrush), impact swallowing, and affect one's ability to speak and eat. It can also cause a burning/tingling sensation in one's mouth, loss of taste, chapped lips, bad breath, a dry/sore throat, and even difficulty wearing dentures.

Your doctor, dentist and pharmacist can provide direction on how to manage symptoms of dry mouth; which may include adjustments to your medications made by your treating physician. Other treatment options are available for dry mouth; these are typically divided into four categories: saliva preservation, saliva substitution, saliva stimulation, and the prevention of caries and/or infection.

**Saliva preservation:** When saliva production is low, it is important to do as much as possible to keep one's mouth as moist as possible and limit things that can dry the mouth out. These include (but are not limited to):

- avoid caffeine, soda, alcohol and tobacco, which all contribute to dry mouth;
- try to breathe through the nose as much as possible, and limit mouth breathing;
- use a humidifier to introduce more moisture into a room or at bedside can be helpful, especially while sleeping.
- check with a doctor before using antihistamines or decongestants, as they can dry the mouth out as well.

**Saliva substitution:** There are many treatment strategies to help replace the moisture that saliva provides to the mouth. These include, but are not limited to:



- drinking water more frequently throughout the day, especially while eating;
- sucking ice chips throughout the day will help the mouth remain as moist as possible;
- a mouthwash can be helpful, but only if it does NOT contain alcohol, as alcohol-based products will only cause further mouth dryness;
- artificial saliva substitutes and oral lubricants (liquids/ sprays/gels) can provide temporary help during eating and speaking;
- moisturize lips with a balm or petroleum jelly.

**Saliva stimulation:** While the aforementioned saliva substitution replaces natural saliva; a saliva stimulant increases the natural production of saliva. Stimulants include, but are not limited to:

- chewing gum (sugar free)
- sugar free mints, lozenges, or other hard candies can also help stimulate the salivary glands;
- prescription medications that help increase salivary flow.

Prevention of dental issues and infection (oral thrush/Candida): Cavities, gingivitis, periodontal disease, and oral infections are common problems of dry mouth. Dry mouth makes plaque control more difficult, so oral care and hygiene are essential in maintaining a healthy mouth. Incorporating a low sugar/low acid diet and daily use of antimicrobial rinses to combat the effects oral dryness has on the teeth and oral tissues. Dentures often harbor fungal infections, so they should be cleaned daily.

Regular visits to the dentist are essential to help manage these issues and maintain a healthy mouth.

#### References:

1 Cersosimo MG, Raina GB, Calandra CR, Pellene A, Gutiérrez C, Micheli FE, Benarroch EE (2011) Dry Mouth: An Overlooked Autonomic Symptom of Parkinson's Disease. Journal of Parkinson's Disease, vol. 1, no. 2, pp. 169-173, 2011



# Drooling

Written by: Brandi La Bonte

While there is much debate about the amount of saliva a person produces in a day; the average seems to be about 30-40ml/hour. A bit more when you are eating, a bit less when you are sleeping. That is about 750ml every day.

If you have Parkinson disease, you may be experiencing sialorrhea (a reduced control of saliva, more commonly known as drooling). If so, you are not alone, research suggests that drooling can be present in 50 of all people with Parkinson's; with a quarter of those experiencing the issue as a frequently occurring problem<sup>1</sup>.

Drooling is the unintentional spillage of saliva from the mouth. Drooling can occur with any condition that:

- impairs neuromuscular control of the muscles around the mouth;
- · increases salivation; or
- · impairs swallowing.

Although the pathophysiology of drooling in Parkinson disease is not completely certain, research suggests that it is the latter, impaired swallowing, that is likely the major contributor of drooling in people with Parkinson disease.

In addition to the psychological complications (embarrassment, social anxiety/isolation, depression), other symptoms can include:

- chapped/dry lips
- softening, damage and/or infection of the skin around the mouth
- bad breath
- dehydration
- speech disturbance
- · poor sense of taste

In more serious cases, people who experience frequent drooling may be more likely to inhale saliva, foods or fluids into their lungs, which can lead to aspiration pneumonia.

#### What can be done?

The good news is that there are things that can be done to help alleviate this issue.

**Medications** – This could be a medication adjustment of one's current regimen (levodopa or dopamine agonists) or a treating physician may prescribe anticholinergics to help dry up excess saliva. The downside to the latter is that this class of drugs often has serious side effects that may outweigh any potential benefit.

**Botox injections** – Injections of botulinum toxin (Botox) directly into one's saliva glands have been used successfully to treat drooling in people with Parkinson's. The effects of Botox typically last three to four months. As with medications, this intervention carries a risk of side effects.

**Speech Therapy** – A visit to a Speech Language Pathologist can be beneficial with assistance in strengthening muscles utilized in speech and swallowing.

Physical/Occupational Therapy – This type of therapy can help improve posture and the overall carriage of one's body which can help prevent a stooped forward posture that can lead to salvia pooling and ultimately drooling.

**Other** – Drinking water more frequently can help "wash down" saliva. While sucking on sugar free hard candies can encourage swallowing. Sugar free as sugary foods increases saliva production.

It is important to discuss issues you may be experiencing with excessive drooling with your treating physician to avoid not only serious complications, but to alleviate potential feelings of anxiety or embarrassment.

#### **References:**

1 Srivanitchapoom, P., Pandey, S., & Hallett, M. (2014). Drooling in Parkinson's disease: a review. Parkinsonism & related disorders, 20(11), 1109–1118. doi:10.1016/j.parkreldis.2014.08.013

# Good Oral Hygiene

Written by: Brandi La Bonte

tudies have indicated that people with a diagnosis of Parkinson disease may have poorer oral hygiene and a greater incidence of infection as compared to the general public<sup>1</sup>. In Parkinson disease good oral hygiene is essential to:

- Maintain comfort
- · Reduce likelihood of bad breath
- Reduce risk of cavities, gum disease and other mouth infections which can further health issues
- Reduce the risk of pneumonia (infection in the lungs from bacteria in the mouth)
- Help manage saliva which can reduce drooling or stimulate saliva flow
- A healthy mouth also contributes to improved chewing, swallowing, speaking, appetite and enjoyment of food

Performing basic oral hygiene tasks can become more challenging as Parkinson disease progresses. In addition to motor-related challenges (such as tremor, rigidity, decreased range of motion), there may also be behavioral changes such as cognition, apathy and depression that can have an impact on good oral hygiene.

# Motor-related challenges may include, but are not limited to:

- Holding/gripping a toothbrush
- Removing cap/squeezing toothpaste from the tube
- Putting dentures in and/or taking them out
- Turning the faucet on/off
- Spitting after brushing
- · Holding a cup for rinsing
- Working with dental floss
- · Clearing mouth of saliva



# What can be done to improve Oral Hygiene?

- 1. Brushing teeth with a fluoride toothpaste twice per day will help to prevent plaque build up and keep the mouth clean of bacteria build up.
- 2. Floss between the teeth once per day to remove food and plaque that the toothbrush may miss.
- 3. Those wearing dentures should be mindful of a continued "good fit" and ensure a proper cleaning.
- 4. Utilizing an alcohol-free mouthwash can not only contribute to a healthy mouth, but also alleviate some occurrences of dry mouth.

There are a myriad of tips, tricks and tools available to help make good oral hygiene easier.

To start, if at all possible, schedule oral care routines around medication "on" times. To address issues with grip and dexterity opt for toothbrushes with a wider handle or electric toothbrushes. Trouble finding a wider-grip toothbrush? Try these innovative tricks of placing the toothbrush inside of a bicycle handlebar grip or tennis ball!





Floss holders, tongue scrapers and toothpaste pumps (including automatic) can be purchased at local shopping centers. Portable oral suction devices are also available to purchase at specialty/adaptive tool stores. A visit to an occupational therapist can be beneficial as he/she can provide simple modifications to one's oral hygiene routine and other adaptive equipment suggestions.

Location, location, location. The bathroom is not the ONLY place

to practice good oral hygiene. In some instances the bathroom may be too small and restrict movement; especially if assistance is needed by another individual. The kitchen and/or dining room table are alternatives. Sitting down at a dining room table, for example, with a basin, glass of water, toothbrush, toothpaste, floss and towel within easy reach can provide more space, be more comfortable and provide a more pleasant experience for everyone.

For those experiencing or who have a loved one experiencing memory and/or apathy issues or who have difficulty remembering the details/steps for good oral hygiene – posting a note in the bathroom (say on a mirror) to remind them of the steps to follow may be beneficial.

# Helping another person with oral hygiene

As Parkinson disease progresses the tasks involved with good oral hygiene may fall to a loved one/care partner. Here are some tips to help:

- Establish a routine for oral hygiene the same time, place and process each time can make the task of good oral hygiene easier.
- 2. It may be easier to brush another person's teeth by standing behind her/him; making sure the person's head is fully supported before starting.
- 3. Brush the front, back and top of each tooth using gentle back and forth brushes. Breaking the brushing of teeth into several shorter spans may be

- beneficial for those who have swallowing/spitting issues.
- 4. Help the person rinse with plain water. For those who cannot rinse, consider gently wiping the inside of the mouth with gauze or a thin washcloth.

#### Don't forget your Dentist!



Regular dental appointments are key to not only maintaining good oral hygiene, but to identify any potential issues that may arise (cavities, infections, etc) and treat them BEFORE they cause unnecessary pain. To ensure a pleasant and productive dentist visit

- Have a discussion with the dental office prior to the appointment to discuss how Parkinson disease may affect the appointment (tremors, rigidity, difficulty speaking, anxiety, etc). An Aware in Care Kit is a great tool to help with this.
- Also be sure to bring up specific issues being experienced (ie: dry mouth, excessive drooling, etc) as the dentist can help address them.
- Providing a medication list to the dentist will ensure that the risk of medication interactions is kept low.
- Request a 45° incline or higher and extra suction to assist with saliva production and swallowing issues.
- If possible schedule the appointment during your peak "on" time.

#### References:

1 Grover, Satbir & Rhodus, Nelson. (2011). Dental management of Parkinson's disease. Northwest dentistry. 90. 13-9.

### Turning the "Impossible" into the Possible

Written by: Brandi La Bonte

Get ready for two days of inspiration, research-based presentations and a gathering of the Parkinson's community that is unparalleled in Alberta! Your two-day Conference experience includes: two keynote speakers, choice of two breakout sessions, Friday evening reception, Saturday hot lunch, and the always popular Ask the Experts panel. Details, including information of conference pricing, transportation and more are available online.

#### **CHECK OUT OUR TOP FIVE REASONS TO ATTEND 2019 HOPE CONFERENCE!**

# 1. It's a pretty big world, but you are NOT ALONE!

With today's technology it is easy to connect with people around the globe; but there really is no substitution for being able to get together with people face-to-face. Attending Hope Conference is a chance to discover that you are not alone in aiming to live well with Parkinson's; there is a world full of people who understand.

#### 2. Break Out of Your Comfort Zone

Apathy is one of those non-motor symptoms that often hard to acknowledge and/or recognize. It is a symptom that can lead not only to isolation, but depression and anxiety as well. While there are those who like to "shake things up" (pardon the pun), for many with Parkinson disease new events, can be a challenge. However, breaking out of your comfort zone can be just the type of action necessary to keep apathy at bay.

#### 3. We've got a lot going on!

Two keynote speakers, Ask the Experts Panel, six breakout session choices, networking and social events are all available to you at Hope Conference.

#### 4. Taking Charge of Your Life

Attending Hope Conference is an investment in living well with Parkinson disease. It is an investment in yourself, your loved ones, and in your life with Parkinson's. It is an acknowledgement that you are not your disease, that there are still things to learn, and that you are worth it.

#### 5. Have fun!

A good conference will help you grow and challenge yourself; a great conference will also be a fun and meaningful experience. The 2019 Hope Conference is a great conference, providing a unique convergence of learning, networking and fun!

#### **MEET OUR KEYNOTE SPEAKERS**



John Baumann is an inspirational speaker, lawyer, author AND our Friday evening Keynote Speaker at 2019 Hope Conference! John was diagnosed with Young Onset Parkinson disease in 2002 at the age of 41. After many years as a high powered, corporate attorney, John

fulfilled a lifelong dream, becoming an internationally recognized inspirational and educational professional speaker on life with Parkinson's. In his presentations he focuses on the positives and moving forward to live life to its fullest, whatever the circumstances. In 2011 he wrote "Decide Success: You Ain't Dead Yet: Twelve Action Steps to Achieve the Success You Truly Desire."



Dr. Ron Postuma, a clinical researcher and movement disorders neurologist treating patients with Parkinson disease and related disorders at the Montreal Neurological Institute and McGill University. Dr. Postuma will be the Keynote Speaker Saturday morning

at our 2019 Hope Conference! Dr. Postuma's research focuses on detecting early stages of Parkinson disease, examining the impact of non-motor symptoms on disease subtype and prognosis, and testing new treatments for non-motor manifestations.

#### 2019 HOPE CONFERENCE

SESSION #	TITLE	DESCRIPTION	PRESENTER
01	Fitness, Frailty, and PD	An in depth look at how fitness is related to Parkinson disease and frailty. This session will look at answering: What is common about fitness and frailty in Parkinson's? What is the frailty scale?	<b>Dr. Naheed Rajabali</b> , BSc (Hon), MSc, MD, FRCPC
02	ОН РООР!	Constipation is a common occurrence in Parkinson disease. This session will cover the medication connection with your poop, why pooping is so important, what is a good poop, and so much more.	<b>Charlene Heavener</b> , RN
03	Recognizing & Managing Behavioural Changes in PD	Parkinson disease is complex and often include behavioural changes in addition to the physical symptoms. This session will help attendees understand the complex interplay of the disease and its treatment.	<b>Dr. Jorge Perez- Parada</b> , MD, FRCPC (Psychiatry)
04	Planning for Future Possibilities	Many of us put off planning for our future or do not address all the areas that require consideration. This session will introduce you to the areas needed to develop a comprehensive future.	<b>Kathryn Brosseau</b> , BSW, RSW
05	Your PD Brain on Exercise: Effects and How To's	An interactive discussion on exercise with a focus on the principles of: consistency, activation, FUNction, manipulation or motor patterns, and quality of life.	Cari Cooke, PT
06	The 5 "W"s of DBS	This session takes an in depth look at the surgical option of Deep Brain Stimulation (DBS) for Parkinson's. Asking: Who? What? When? Where? and Why?	<b>Michelle Waldron</b> , RN, BScN

#### Annual General Meeting

Saturday, May 25, 2019 Edmonton, AB

Membership needed to be purchased by April 24, 2019 to vote.

Membership may still be purchased after that date to receive Member pricing for Conference.

If you plan on attending the AGM please RSVP no later than 12PM on Friday, May 17.

To RSVP please call toll-free 1-800-561-1911 or email info@parkinsonassociation.ca

FRIDAY, MAY 24			
6:30PM - 7:00PM	Hope Conference Registration		
7:00PM - 8:00PM	Keynote Speaker: <b>John Baumann</b>		
8:00PM - 9:00PM	Hope Conference Reception		
SATURDAY, MAY 25			
8:00AM - 8:30AM	AGM Registration		
8:30AM – 9:15AM	AGM		
8:45AM – 9:30AM	Hope Conference Registration		
9:30AM – 9:45AM	Hope Conference Welcome		
9:45AM – 10:45AM	Keynote Speaker: <b>Dr. Ronald Postuma</b>		
10:45AM - 11:00AM	Break		
11:00AM - 12:00PM	Breakout Session #1		
12:00PM - 12:45PM	Lunch		
12:45PM - 1:45PM	Ask the Experts Q&A Panel		
1:45PM - 2:00PM	Break		
2:00PM - 3:00PM	Breakout Session #2		

For more information or to register visit parkinsonassociation.ca/hopeconference

# 2019 HOPE CONFERENCE REGISTRATION FORM

REGISTRATION FORM			
Delegate #1 Name:	Delegate #2 Name:		
Address:			
City, Province:	Postal Code:		
Phone:			
DELEGATE INFORMATION (please circle)			
Delegate #1	Delegate #2		
Person with PD	Person with PD		
Person with Parkinson Plus	Person with Parkinson Plus		
Care Partner/Family Member/Friend Healthcare Professional	Care Partner/Family Member Healthcare Professional		
HOT LUNCH OPTION (please circle)			
· · · · · · · · · · · · · · · · · · ·	Beef Chicken Vege	tarian	
Other Food Allgeries/Restrictions:	Other Food Allgeries/Restrictions:		
CHOOSE YOUR BREAKOUT SESSIONS			
Please indicate the numbers of your TWO (2) breakout session	n choices plus an alternate. Though e	every effort w	vill be made
to ensure your top choices; breakout sessions will be filled			
breakout sesion number (located on the website and in t	he brochure):		
Delegate #1:			
Session #1 Choice	Session #2 Choi	ce	
Delegate #2:	6 1 40 61 1		
	Session #2 Choi		
ANNUAL GENERAL MEETING	CONFERENCE PRICING	ce	
YES! I/We will attend the Annual General			Ć TOTAL
	\$150/Member (AFTER May 5)	Quantity	\$ TOTAL
Meeting.  Membership peeded to be purchased by April 24, 2019 in order to vote at the AGM	\$150/Member (AFTER May 5) \$180/Non-Member (AFTER May 5)		\$ TOTAL
Meeting.  Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on	\$150/Member (AFTER May 5) \$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership		\$ TOTAL
Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.	\$180/Non-Member (AFTER May 5)		\$ TOTAL \$
Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on Conference pricing.	\$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership		
Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on Conference pricing.  PAYMENT METHODS (or register online at www.page)	\$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership		
Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on Conference pricing.	\$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership		
Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on Conference pricing.  PAYMENT METHODS (or register online at www.pathon will pay by cheque. Payable to Parkinson Association of Alberta; drop off with a Client Services Coordinator or mail in (120, 6835 Railway St SE, Calgary, AB T2H 2V6)	\$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership  orkinsonassociation.ca)	Quantity	
Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on Conference pricing.  PAYMENT METHODS (or register online at www.pa	\$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership	Quantity	
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Membership needed to be purchased by April 24, 2019 in order to vote at the AGM.  Membership may be still be purchased after that date to receive the Member rate on Conference pricing.  PAYMENT METHODS (or register online at www.pathon 1 will pay by cheque. Payable to Parkinson Association of Alberta; drop off with a Client Services Coordinator or mail in (120, 6835 Railway St SE, Calgary, AB T2H 2V6) only.  I will pay by cash. Drop off payment & form with Client	\$180/Non-Member (AFTER May 5) \$25 PAA 2019 Membership  orkinsonassociation.ca)  Name as it appears	<b>Quantity</b> Son card	

# **SUPPORT GROUPS**

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

ALBERTA		1-800-561-1911	
ARTA CHARITABLE FOUNDATION'S TELE-	SUPPORT GROUPS		
3 <sup>rd</sup> Wednesday - <b>Care Partners</b>	6:30 pm – 7:30 pm	Advance registration is required to receive call-in instructions & a passcode; call the above number.	
3 <sup>rd</sup> Thursday - <b>General Parkinson's</b>	10:00am – 11:00am		
4 <sup>th</sup> Thursday - <b>Parkinson's Plus Syndromes</b>	10:00am – 11:00am	instructions & a passcode, can the above number.	
CALGARY REGION		403-243-9901	
AIRDRIE			
3 <sup>rd</sup> Monday	10:00 am – 11:30 am	Cam Clark Ford – 1001 Highland Park Blvd	
CALGARY			
1st Tuesday – <b>Northwest</b>	10:00 am – 11:30 pm	Hope Lutheran Church – 3527 Boulton Rd NW	
1st Thursday – <b>Northeast</b>	10:00 am – 11:30 am	Ascension Lutheran Church – 1432 - 19 St NE	
2 <sup>nd</sup> Tuesday – <b>Southeast</b>	10:00 am – 11:30 am	PAA Calgary Office – 120, 6835 Railway St SE	
3 <sup>rd</sup> Tuesday - <b>Care Partners</b>	1:30 pm – 3:00 pm	PAA Calgary Office – 120, 6835 Railway St SE	
3 <sup>rd</sup> Thursday - <b>Southwest</b>	10:00 am – 11:30 am	Riverpark Church – 3818 - 14A St SW	
4 <sup>th</sup> Tuesday - <b>Southeast</b>	10:00 am – 11:30 am	PAA Calgary Office – 120, 6835 Railway St SE	
4 <sup>th</sup> Tuesday - <b>Young Onset</b>	7:00 pm – 9:00 pm	Hope Lutheran Church – 3527 Boulton Rd NW	
CANMORE	:		
2 <sup>nd</sup> Thursday	1:30 pm – 3:00 pm	Bow River Lodge – 920 13 St	
COCHRANE			
2 <sup>nd</sup> Thursday	10:00 am – 11:30 am	St. Andrew's United Church – 128 – 1st St SE	
NANTON			
4 <sup>th</sup> Thursday	10:00 am – 11:30 am	St. Cecilia's Catholic Church – 2308 – 19 <sup>th</sup> St	
STRATHMORE			
1 <sup>st</sup> Thursday	1:30 pm – 3:00 pm	Hope Community Church – 245 Brent Blvd	
EDMONTON REGION		780-425-6400	
CAMROSE			
2 <sup>nd</sup> Wednesday	3:30 pm – 5:30 pm	City Lights Church – 4920 – 48 St	
EDMONTON			
1 <sup>st</sup> Wednesday - <b>South</b>	1:00 pm – 3:00 pm	Rutherford Heights – 949 Rutherford Rd	
1st Thursday - Men's Care Partners	10:00 am – 12:00 pm	PAA Edmonton Office – 11209 – 86 St NW	
1st Thursday - Women's Care Partners	10:00 am – 12:00 pm	PAA Edmonton Office – 11209 – 86 St NW	
3 <sup>rd</sup> Wednesday - <b>Central</b>	7:00 pm – 9:00 pm	PAA Edmonton Office – 11209 – 86 St NW	
FORT SASKATCHEWAN			
4 <sup>th</sup> Tuesday	1:00 pm – 3:00 pm	<b>Pioneer House</b> – 10102 - 100 Ave	
LEDUC	·		
4 <sup>th</sup> Tuesday	6:30 pm - 8:30 pm	Telford House – 4907 - 46 St	
PARKLAND (SPRUCE GROVE/STONY PLAIN	) )		
4 <sup>th</sup> Thursday	10:00 am – 12:00 pm	<b>Stony Plain</b> – 107, 4613 – 52 Ave	



#### AT A GLANCE

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

SHERWOOD PARK				
2 <sup>nd</sup> Tuesday	1:00 pm – 3:00 pm	Bethel Lutheran Church – 298 Bethel Dr		
ST. ALBERT				
3 <sup>rd</sup> Tuesday	10:00 am – 12:00 pm	St. Albert 55+ Club – 7 Tache St		
WESTLOCK				
Last Monday	1:30 pm – 3:30 pm	<b>Room 140, Provincial Bldg</b> – 2, 10003 – 100th St		
GRANDE PRAIRIE REGION		780-882-6640		
GRANDE PRAIRIE				
2 <sup>nd</sup> Wednesday	2:00 pm – 3:30 pm	<b>Grande Prairie Care Centre</b> – 9705 – 94 Ave		
LETHBRIDGE REGION		403-317-7710		
LETHBRIDGE				
3 <sup>rd</sup> Thursday	2:00 pm – 4:00 pm	<b>Lethbridge Senior Citizens Org.</b> – 500 – 11th St S		
LLOYDMINSTER REGION		780-808-5006		
BONNYVILLE				
3 <sup>rd</sup> Friday	11:00 am – 12:30 pm	Neighbourhood Inn – 5011 66 St		
LLOYDMINSTER				
2 <sup>nd</sup> Monday - <b>Care Partners</b>	10:00 am – 11:00 am	Southridge Community Church – 5701 – 41 Street		
4 <sup>th</sup> Tuesday	2:00 pm – 4:00 pm	Southridge Community Church – 5701 – 41 Street		
WAINWRIGHT				
2 <sup>nd</sup> Tuesday	2:00 pm – 3:00 pm	<b>Provincial Building</b> – 810 – 14th Ave		
MEDICINE HAT REGION		403-526-5521		
MEDICINE HAT				
4 <sup>th</sup> Tuesday	1:30 pm – 3:00 pm	Crossroads Church – 1340 – 22 St SE		
RED DEER REGION		403-346-4463		
CASTOR	:			
4 <sup>th</sup> Tuesday (Feb, Apr, Jun, Aug, & Oct)	1:30 pm – 3:30 pm	Paintearth Lodge – 4501 – 55 Ave		
LACOMBE	:			
4 <sup>th</sup> Wednesday of the month	10:00 am – 12:00 pm	Wolf Creek Community Church – 4110 Hwy 12		
OLDS	:			
2 <sup>nd</sup> Wednesday of the month	1:30 pm – 3:30 pm	Sunrise Village – 5600 Sunrise Cres		
RED DEER	:			
3 <sup>rd</sup> Wednesday of the month	10:00 am – 12:00 pm	Davenport Church of Christ – 68 Donlevy St		
ROCKY MOUNTAIN HOUSE	:			
2 <sup>nd</sup> Thursday (Mar, Jun, Sept & Dec)	2:00 pm – 4:00 pm	Immanuel Lutheran Church – 5236 – 54 St		
THREE HILLS				
3 <sup>rd</sup> Wednesday (Feb, Apr, Jun, Sep & Nov)	1:30 pm – 3:30 pm	Community Drop In Centre		







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

Personal Information				
□ Mr. □ Mrs. □ Miss □ Dr.				
First Name: Address: Prov: Prov: Phone: Email: Person Living with PD	Postal: amily Member/Friend			
Membership  Membership is \$25 annually and runs from January 1 to De  □ I wish to BECOME a member □ I wish to RENEW my □ I would like my Parkinson Pulse Magazine mailed to me	y Membership			
Donation  Donations of \$20 and up will be receipted.  □ I wish to make a DONATION in the amount of: \$ □ In Memory of Please send a notification of this gift to (name and address)	_ In Honor of			
Payment  ☐ Enclosed please find my cheque (made payable to Parki or cash for \$  ☐ Please bill my: ☐ Visa ☐ Mastercard ☐ American Exp. Name on Card:  Card Number:	press			

# You Ask, We Answer Pricing 2019 Hope Conference Pricing

Written by: Brandi La Bonte

We have been fielding a few calls and questions from across the province all asking the same question – why is Hope Conference more expensive this year?

The short answer is that... it is and it isn't. It all comes down to context.

It is, in that it is more expensive than the Regional Hope Conferences we held last year and in a few previous years. It isn't, in that it is less expensive than our last Provincial Hope Conference.

Let us explain. This year it was determined to host a PROVINCIAL Hope Conference once again in an effort to bring the Parkinson's Community from across the province together, instead of regional conferences which have been held simultaneously in multiple locations across the province. Regional Hope Conferences were held in 2015, 2017 and 2018 with varying degrees of success. Our last Provincial Hope Conference was held in 2014 and saw over 200 people attend from across the province! Feedback from that event was extremely positive and we have since heard from many people across this great province that they would like to have another opportunity to gather together as a larger Alberta Parkinson's Community.

Hosting a provincial conference meant a change in location to a hotel setting to make it easier on those attendees travelling from outside the City of Edmonton. While a two-day conference format also allowed for out-of-town guests to participate without having to leave in the wee hours of the morning or choose not to come at all because it would be too much travelling for one day. These items, unfortunately do add to the cost of an event, but on the other hand there is so much more to experience!

Our keynote speakers were selected by the Hope Conference Committee based on feedback from our clients asking for inspiration and research! John Baumann, our inspirational speaker and person with Parkinson's himself, has an inspiring story to tell; while Dr. Postuma's research presentation will bring hope for a brighter future in Parkinson disease.

A Friday evening reception is a new addition and was added based on your feedback indicating a desire for more time to get together and socialize with friends, old and new! Your choice of two Breakout Sessions from six options, the always popular Ask the Experts Panel and a hot lunch round out the two-day event.

We hope that helps answer the question. If you have any other questions or would like to register for Hope Conference please reach out to your Regional Client Services Coordinator or visit us online at parkinsonassociation.ca/hopeconference



Join us to talk with people across Alberta living with and affected by Parkinson disease and Parkinson's Plus Syndromes.











Pick up the phone to connect to the support you need right from the comfort of your home!



**Tele-Support Groups** 



# 28TH ANNUAL PARKINSON TULIP GOLF TOURNAMENT



THURSDAY, JULY 4, 2019 • SILVER SPRINGS GOLF & COUNTRY CLUB



# REGISTRATION 11:30AM Registration and silent auction open, followed

by a BBQ lunch



1:00PM

Take a shot at hole-in-

SHOTGUN START



DINNER

**6:30PM**Enjoy a delicious buffet dinner by Silver Springs Golf & Country Club

More information and other great events at

PARKINSONASSOCIATION.CA/TULIPTOURNAMENT
OR CALL (403-243-9901)

# 2019 HOPE CONFERENCE

# Turning the "Impossible" into the

**POSSIBLE** 

MAY 24 & 25, 2019 EDMONTON, AB



John Baumann



Dr. Ronald Postuma

# MPOSSIBLE

For more information please refer to page 14. Visit us at parkinsonassociation.ca/hopeconference