

Parkinson

PULSE

Connecting people living with Parkinson disease in Alberta



BEYOND THE TREMOR

Non-Motor Symptoms of Parkinson's



Cover Story P.6

What Are Non-Motor Symptoms?

Research in Alberta Series P.12

Supporting Parkinson Disease Research

- an evening to inspire -



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Spring 2015

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Parkinson Alberta



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

Parkinson Alberta (PA) helps make every day better for Albertans affected by Parkinson disease. We provide support services, education, advocacy and funds for research.

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Parkinson Pulse is available (both past and present issues) as a free download via our website and in hard copy to our Members.

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

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From the Desk of **THE CEO**

Alberta has a Parkinson disease incidence rate of 244.35/100,000, and with 2014 population of 4.146 million, that means that there are approximately 10,130 individuals in Alberta who have been diagnosed with Parkinson's. That is 10,130 individuals plus their families and care partners who shouldn't have to face Parkinson's alone, who shouldn't have to feel afraid or invisible. That is 10,130 individuals and their loved ones to whom Parkinson Alberta is committed, to whom we will offer the very best in support services and education.

As the population of Alberta not only surges, but ages, the number of Albertans being diagnosed with Parkinson's increases. This in turn has more people accessing our supports and services than ever before and inevitably has an impact on both our human and financial resources.

Our 2015 budget is \$2.2 million, the greater part of which is committed to the direct benefit of people living with and affected by Parkinson disease via support services, programs, and educational opportunities as well as contributions to research. Like many self-supporting non-profit organizations, securing financial funding is a huge issue. Parkinson Alberta receives no government funding outside of grants we apply for, but do not always receive. In fact 100% of our revenues are generated by fundraising events, donations, grants and memberships. Unfortunately, the current state of the provincial economy suggests that it will be a tough road ahead.

It will be tough, but we will continue to do what we do best – offer Albertans the quality support, programs and education that encompasses one's entire Parkinson's journey. We will continue to help and expand your Parkinson's knowledge by delving into a wide-range of PD-related topics from Parkinson's 101 to medications to planning for the future to those topics that go *Beyond the Tremor*—non-motor symptoms (page 8). These "invisible" symptoms are often just as, if not more so, detrimental than the more physical, motor symptoms of Parkinson's.

We will continue to offer high-calibre educational opportunities, like our newest offering the *2015 Regional Hope Conference* (page 8). This conference, for people with Parkinson's, their families and care partners, health professionals and students in the health field, will take

place in all seven of our Regions and offer an in-depth look at non-motor symptoms.

We will continue to provide a variety of ways for you and your family to get involved. Sign up a foursome or help us recruit a sponsor for our golf tournament. Become a champion through our research campaign or support our daily activities via Circle of Help. Or, tell us your story like George Nemeth did (page 4).

Volunteering is another great way to get involved and make a difference. From Peer-to-Peer volunteers, to office and program assistance, to our multitude of events; giving Parkinson Alberta your gift of time and talent makes a real, tangible difference not only for our organization, but for the entire Parkinson's community!

And then, of course, we have our **2015 Flexaire Parkinson Step 'n Stride**. Last year's walk was a tremendous success! Not only did we welcome provincial sponsor Flexaire, we raised over \$300,000! This year we're aiming higher, reaching further. To help us achieve our goals we are reaching out to engage even more people than ever before. From step-by-step online registration instructions (page 14) to our "Why You Walk" video campaign (page 20); it has never been easier, or more fun to get involved!

It won't be an easy road this year, but we are committed. . . committed to offering support, programs and educational opportunities, committed to making every day better for Albertans living with Parkinson disease, committed to being there for every step of one's PD journey. Committed to you and your family; and to the thousands of other individuals and families just like yours and with your help we will persevere.

We are Albertans for Albertans. We've always been the ones to dig deep, go the extra mile and stand shoulder to shoulder with our neighbors to make every day a little bit better. We are Albertans, and together we will strive for a better today and tomorrow for people with Parkinson disease.





ONE DAY AT A TIME

By: *George Nemeth*



I'm a baby-boomer, born in 1945 to Hungarian parents, in a family of eleven I was raised on a farm around Coaldale. Farm life was a good life but it exposed me to all kinds of chemicals used on the farm as well as exposure to sun and dust. At the age of about seven years, as I recall, I fell down some basement steps and bumped my head, and that is when I recall developing a speech impediment. I had severe headaches and dizzy spells as a child but eventually out grew them. I will never forget as a teenager riding four miles to school on my 1947 Harley Davidson, they heard me coming long before they saw me.

I left home suddenly about 1965 having been accepted into the NAIT Forestry Program. One year in Edmonton and two years at Hinton. After graduating from NAIT I went to work for the Federal Department of Forestry in Calgary, where I met my wife to be, Dianne. Our first meeting was to say the least 'heavenly' as we both knew instantly that this was to be the "the one". We got married in 1969 and moved back to Lethbridge where I worked for the Provincial Department of Environment. I got tired of the Government always transferring and moving me around and decided to settle down in a Trade. I apprenticed in Sheet Metal for four years which also included HVAC (Heating, Ventilation, and Air Conditioning) Service Technology. I also wrote for and received my Certificate in Refrigeration. In these trades I was exposed to asbestos, welding smoke, refrigerants and household dust.

We have travelled to Hawaii twice and thoroughly enjoyed it. My wife has been to Holland, travelled extensively in Canada and in the USA with her Managerial Position with the City of Lethbridge (now retired). We have two children. We are now helping with and really enjoying two grandchildren. Our daughter is an Instructor at the Lethbridge College. Our son is deceased.

After retiring in 2009, at the age of 60 years, I noticed a slight tremor developing in my jaw. The local neurologist diagnosed it as an essential tremor. I cannot imagine why it was essential? Upon my insistence I finally got referred to another neurologist at the Calgary Movement Clinic in the Foothills Hospital, where the diagnosis of having Parkinson disease went from yes I do, to no I don't, you have Dystonia; to no, wait, you do have Parkinson disease with some evidence of Dystonia. I was started on sinmet and pramipexole and I also get Botox injections for the jaw tremor. I was diagnosed with Parkinson (Stage one) going by the symptoms of a tremor, slower left side body movements, less facial expressions, always or often being very tired and being soft spoken. On top of Parkinson disease, I also have problems with deteriorated and herniated disks in my lower back causing a lot of pain in my back, right leg and foot. In addition, I had a nerve sheath tumor removed in another part of my spine in 2008.

My hobbies are reading, photography, yard work, grand parenting and going on walkabouts. Having Parkinson disease seems unreal and mysterious as there are no clear cut tests for it and the symptoms vary greatly. People who have always known me cannot even tell I have it. I found that the secret to life is to carry only one day at a time on your shoulders; rather than giving up and saying it is too much.

If you would like to share your story, please email communications@parkinsonalberta.ca or talk to your regional Client Services Coordinator.

Ask the EXPERTS + A

Parkinson Alberta has gathered an exemplary team of experts to answer your PD questions in a feature on our website aptly named "Ask the Experts". Our experts address questions on everything from symptoms and treatments, to medications and research, to alternative therapies.

Question: My dad was diagnosed with PD early 2011. He is 56 years old. He was put on Sinemet 3 times a day. He has lost most of his movement on the right side, with stiffness. He is losing weight constantly and has lost complete confidence as communication has become challenging too. He has constant anxiety attacks and no desire to do anything. What treatments would you suggest?

Answer: Parkinson disease is a multi-system disease, meaning that it affects multiple areas of the nervous system. In addition to motor slowness, stiffness and gait problems, it can cause psychiatric symptoms (such as anxiety and depression), fatigue, apathy, and autonomic dysfunction (constipation, bladder problems, and low blood pressure). Treatment involves use of drugs like Sinemet, which will help the motor symptoms. Dose needs to be gradually increased until benefit is seen. There is also treatment for the other symptoms. For example, anxiety will respond to anti-depressants, low blood pressure can be treated with increased fluid and salt intake, etc. The physician needs to ask about all the symptoms of PD to develop the best treatment plan. Involvement of a multidisciplinary team such as physiotherapy, speech therapy, dietary, psychiatry, and other specialists is also important. This type of comprehensive care is available through the Movement Disorders Clinics in Edmonton and Calgary. Parkinson Alberta, as well as other societies can provide information and resources on all aspects of the condition.

Question: I've had PD for about 8 yrs. With it came a rare happening called CAMPTOCORMIA. It makes you bend over like the Hunchback of Notre Dame. It does not happen when one sleeps or sits down, only when I walk. Some doctors say it is caused by the stomach muscles pulling one forward in a bent over position. No one seems to have knowledge about any treatments to make the camptocormia not as bent and rigid that it is. Have you heard of this and do you have any avenues of treatment or suggestions? Right now this is worse at this time than the PD.

Answer: The term camptocormia can be loosely translated into the term "bent-trunk". It refers to severely stooped or bent posture and not to a specific underlying disorder. Its basis is likely different depending on the cause; for instance, it can be related to disorders that can cause weakness (such as disorders of muscle, the neuromuscular junction or motor nerves or neurons). If weakness is greater in the para-spinal and back muscles this can lead to imbalanced forces acting on the spine and a bent position. Structural changes in the bones of the spine (for example fractures leading to compression) can also lead to a bent position. These mechanisms are in contrast to an active contraction of muscles, such as seen in dystonias, disorders that lead to active muscle contractions. Camptocormia is often associated with diseases that cause parkinsonism (Parkinson's disease and multi-system atrophy among others) and can occur in up to 10% of patients with Parkinson's disease. Treatment approaches would differ depending on the cause. Camptocormia should be evaluated by a neurologist, or other experienced clinician, who can coordinate an evaluation aimed at identifying the likely mechanism. In people with parkinsonism, especially those with Parkinson's disease, modification of dopaminergic medications can be tried. In camptocormia due to dystonia, botulinum toxin injections might be helpful. The role of physiotherapy is unclear. The surgery is not done on individuals with mild Parkinson's, as medications such as Sinemet work very well. The medications never "stop" working; as the condition progresses, the medications become less effective and need to be adjusted appropriately, and surgery considered.

PD HELPLINE

Call 1-877-243-9992

Monday to Friday
8:30 am till 4:30 pm
Free from anywhere in Alberta

If you have a question you would like to ask, visit us online at: parkinsonalberta.ca/ask-the-experts

BEYOND THE TREMORS

What Are Non-Motor Symptoms?



Parkinson disease is the second most common neurodegenerative disorder after Alzheimer's disease, with an incidence rate that is predicted to rise by almost 50% in the next 20 years. Few people truly understand what it means to have Parkinson disease or that it is so much more than visible tremors.

Imagine for a moment, if you will, not being able to smell or taste your favorite home-baked dessert; or the fear you might feel by not being able to smell smoke from a fire in your home. Envision night after night of not being able to sleep, or, alternatively unexpectedly falling asleep in the middle of the day – during your son's hockey game, your granddaughter's ballet recital or during lunch with friends. While different for everyone, symptoms like these go beyond the tremors and are a reality for people with Parkinson disease.

Unlike the motor symptoms of Parkinson's (resting tremor, slowness of movement, rigidity and postural instability), non-motor symptoms are not as apparent to others. These "invisible" symptoms are often just as, if not more so, detrimental than the more physical, motor symptoms of Parkinson's. It is believed by many researchers that these "invisible" symptoms may actually precede a Parkinson disease diagnosis – by years.

While it is important to note that the following symptoms **DO NOT** necessarily mean one has or will develop Parkinson disease; the most recognizable early symptoms of Parkinson's include:

- » Loss of sense of smell
- » Frequent constipation
- » Low blood pressure when standing up
- » Mood disorder
- » Sleep disturbances

What are non-motor symptoms?

Non-motor symptoms are those symptoms that do not involve movement or mobility. The range of non-motor symptoms is fairly large and includes sleep disturbances, mood disorders, psychosis, cognitive impairment, dementia and autonomic dysfunctions.

From excessive daytime sleepiness to insomnia, **sleep issues** are considered an inherent part of Parkinson's with prevalence rates ranging from 75-98% in the PD population. **Mood disorders** including anxiety and depression (see our Winter 2015 issue for more on this subject) and apathy often play a role (to varying degrees) in life with Parkinson disease.

Psychosis affects roughly 40% of people with Parkinson's who are receiving dopamine replacement medications and may affect up to 10% of patients who are not receiving dopaminergic medications. Psychosis in PD is characterized primarily by hallucinations (mostly visual though they can include tactile, auditory and olfactory), delusions and illusions.

Autonomic Dysfunctions are 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.

It is important to talk to your doctor about any and all symptoms you may be experiencing, particularly if they are troublesome for you. The following questionnaire can help you talk to your doctor about non-motor symptoms you may be experiencing.

Have you experienced any of the following in the last month?

	yes	no		yes	no
1. Dribbling of saliva during the daytime.....	<input type="checkbox"/>	<input type="checkbox"/>	15. Difficulty concentrating or staying focused	<input type="checkbox"/>	<input type="checkbox"/>
2. Loss or change in your ability to taste or smell.....	<input type="checkbox"/>	<input type="checkbox"/>	16. Feeling sad, 'low' or 'blue'	<input type="checkbox"/>	<input type="checkbox"/>
3. Difficulty swallowing food or drink or problems with choking.....	<input type="checkbox"/>	<input type="checkbox"/>	17. Feeling anxious, frightened or panicky	<input type="checkbox"/>	<input type="checkbox"/>
4. Vomiting or feelings of sickness (nausea).....	<input type="checkbox"/>	<input type="checkbox"/>	18. Feeling less interested in sex or more interested in sex	<input type="checkbox"/>	<input type="checkbox"/>
5. Constipation (less than 3 bowel movements a week) or having to strain to pass a stool (feces).....	<input type="checkbox"/>	<input type="checkbox"/>	19. Finding it difficult to have sex when you try..	<input type="checkbox"/>	<input type="checkbox"/>
6. Bowel (fecal) incontinence	<input type="checkbox"/>	<input type="checkbox"/>	20. Feeling light headed, dizzy or weak standing from sitting or lying	<input type="checkbox"/>	<input type="checkbox"/>
7. Feeling that your bowel emptying is incomplete after having been to the toilet.....	<input type="checkbox"/>	<input type="checkbox"/>	21. Falling	<input type="checkbox"/>	<input type="checkbox"/>
8. A sense of urgency to pass urine makes you rush to the toilet	<input type="checkbox"/>	<input type="checkbox"/>	22. Finding it difficult to stay awake during activities such as working, driving or eating.....	<input type="checkbox"/>	<input type="checkbox"/>
9. Getting up regularly at night to pass urine...	<input type="checkbox"/>	<input type="checkbox"/>	23. Difficulty getting to sleep at night or staying asleep at night.....	<input type="checkbox"/>	<input type="checkbox"/>
10. Unexplained pains (not due to known conditions such as arthritis)	<input type="checkbox"/>	<input type="checkbox"/>	24. Intense, vivid dreams or frightening dreams	<input type="checkbox"/>	<input type="checkbox"/>
11. Unexplained change in weight (not due to change in diet)	<input type="checkbox"/>	<input type="checkbox"/>	25. Talking or moving about in your sleep as if you are 'acting' out a dream.....	<input type="checkbox"/>	<input type="checkbox"/>
12. Problems remembering things that have happened recently or forgetting to do things	<input type="checkbox"/>	<input type="checkbox"/>	26. Unpleasant sensations in your legs at night or while resting, and feeling that you need to move.....	<input type="checkbox"/>	<input type="checkbox"/>
13. Loss of interest in what is happening around you or doing things.....	<input type="checkbox"/>	<input type="checkbox"/>	27. Swelling of your legs.....	<input type="checkbox"/>	<input type="checkbox"/>
14. Seeing or hearing things that you know or are told are not there	<input type="checkbox"/>	<input type="checkbox"/>	28. Excessive sweating	<input type="checkbox"/>	<input type="checkbox"/>
			29. Double vision	<input type="checkbox"/>	<input type="checkbox"/>
			30. Believing things are happening to you that other people say are not true	<input type="checkbox"/>	<input type="checkbox"/>

Developed and validated by the International PD Non Motor Group

REGIONAL Hope Conference

Parkinson Alberta is excited to offer our first ever live webcast at our newest educational offering: the 2015 Regional Hope Conference! This take on our popular Hope Conference invites those from across the province to attend this high-calibre educational event in one of seven regions across the province.

Keynote Speaker: Dr. Becky Farley, PT, MS, Ph



Dr. Farley received a PhD in Neuroscience from the University of Arizona, a Master of Science in Physical Therapy from the University of North Carolina, and a Bachelor of Physical Therapy from the University of Oklahoma. She has over 30 years of experience in neurorehabilitation, and is currently the CEO/Founder of the non-profit Parkinson Wellness Recovery (PWR!)

and a Physiology Associate at the University of Arizona. During her post-doc, Dr. Farley studied bradykinesia, developed the LSVT® BIG exercise program, and completed an NIH funded randomized clinical trial documenting its' short-term efficacy (3-months).

After lunch attendees will hear from two more speakers presenting on topics related to non-motor symptoms in Parkinson disease. Many people are familiar with the motor symptoms of Parkinson disease (tremor, slowness of movement, etc); however the non-motor symptoms can often be just as troublesome and detrimental to

quality of life. Conference attendees will hear from experts in Parkinson disease speaking about this often overlooked entity in Parkinson's.

This conference is for people with Parkinson's, their families and care partners, health professionals and students in the health field.

The general itinerary for the 2015 Regional Hope Conference is listed below, for a more detailed version of what is taking place in your region please visit our website.

- 7:30 – 8:30AM – Annual General Meeting Registration**
- 8:30 – 9:45AM – Annual General Meeting**
- 9:00 – 10:00AM – Regional Hope Conference Registration**
- 9:45 – 10:00AM – Break**
- 10:00 – 11:30AM – Keynote Speaker: Dr. Becky Farley**
- 11:30 – 12:30PM – Lunch**
- 12:30 – 1:45PM – Plenary Speaker #1**
- 1:45 – 2:00PM – Break**
- 2:00 – 3:15PM – Plenary Speaker #2**
- 3:15 – 3:15PM – Closing Remarks**

2015 Regional Hope Conference fees are \$50 for Members and \$85 for Non-Members and includes lunch. For more information or to register fill out and mail in the form on the following page, talk to your Regional Client Services Coordinator, call 1-800-561-1911 or visit:

www.parkinsonalberta.ca/2015-regional-hope-conference

2015 REGIONAL HOPE CONFERENCE REGISTRATION FORM

Delegate #1 Name (First & Last)

Delegate # 2 Name (First & Last)

Address

City

Province

Postal Code

Phone

Email

DELEGATE INFORMATION - Circle the term which best describes each delegate & indicate any dietary restrictions

Delegate #1: Person w/PD Newly Diagnosed Young Onset Care Partner Healthcare Professional

Dietary Restrictions: _____

Delegate #2: Person w/PD Newly Diagnosed Young Onset Care Partner Healthcare Professional

Dietary Restrictions: _____

CHOOSE YOUR REGION - Circle the Region in which you will be attending

CALGARY EDMONTON GRANDE PRAIRIE LETHBRIDGE LLOYDMINSTER MEDICINE HAT RED DEER

CONFERENCE PRICING

of Memberships _____ x \$25 = _____ I/we will be attending the AGM

of Delegates Member _____ x \$50 = _____

of Delegates Non-Member _____ x \$85 = _____

TOTAL _____

PAYMENT METHOD - Circle your method of payment

Cheque (payable to Parkinson Alberta) Amex MasterCard Visa

Name as it appears on card

Card Number

Expiry Date

PLEASE SEND REGISTRATION FORM & PAYMENT TO:

Regional Hope Conference Registration - 102, 5636 Burbank Cres SE - Calgary, AB T2H 1Z6

SLEEP ISSUES IN PARKINSON DISEASE

Sleep is an important part of living well. People living with Parkinson disease (PD) often experience problems with sleep. Some are associated with PD itself, while others may be linked to the medications used to treat the symptoms of PD. Problems that people living with PD may have with sleep include the following:

- » trouble falling asleep and/or trouble staying asleep
- » sleepiness during the day including falling asleep suddenly (“sleep attacks”)
- » vivid dreams or nightmares; acting out dreams
- » talking, yelling or kicking while sleeping
- » frequent waking up to go to the bathroom
- » jerking, cramping or moving of the legs
- » trouble turning or shifting in bed

If you are having trouble with sleep, make sure your doctor/healthcare team is aware of the specific problems you are having.

- » Sleep difficulties may be related to the medications you are taking for PD. Your doctor may be able to change the dose, type of medication or timing of medication to help your sleep
- » You may learn tips to better cope with these problems from your healthcare team
- » If you have a bed partner, it is important to include them in this conversation as their sleep may be affected by your sleep challenges

Tips that may help you get a good night’s sleep:

- » establish a sleep routine – go to bed and get up at the same time every day
- » avoid drinks containing caffeine within 6 hours of bedtime
- » use the bedroom for sleeping not reading, watching TV, using the computer or working
- » drink a glass of warm milk before going to bed if getting up to use the bathroom at night is not a problem for you
- » if you have trouble getting in/out of bed or with turning in bed, satin sheets and/or pajamas may be helpful
- » exercise during the day, but avoid vigorous exercise just before going to sleep
- » try not to take long naps during the day
- » take a warm – not hot – bath
- » have a massage or participate in other relaxing activities

EVENTS

+ updates

UPCOMING EVENTS

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

Sip, Sample, Support fundraiser

Parkinson Alberta is delighted to host our 2nd annual Sip, Sample, Support fundraiser in Calgary on June 6, 2015. Taking place at the visually stunning Canadian Sports Hall of Fame, this year's event will once again feature an array of wines and appetizers as well as a silent auction all in support of Parkinson's. Tickets are \$75/person and are available online or by calling 403-243-9901.

PA Medicine Hat Support Group Charity Garage Sale

Your treasure awaits at the 3rd annual PA Medicine Hat Support Group Charity Garage Sale on June 26 & 27, 2015! As always, items are not priced and are sold by donation. Please note that items can be dropped off on June 25 from 9:00AM - 3:00PM at the Kin Social Room. We will not accept wearables, furniture or baby items (such as strollers, cribs, infant carriers, car seats & high chairs).

24th Annual Parkinson's Tulip Golf Tournament

Get your clubs ready and hit the links for the 24th Annual Parkinson's Tulip Golf Tournament! The day includes a light lunch; 18 holes of golf at the beautiful Sirocco Golf Course; a delectable buffet dinner; silent and live auctions. To register or for more information on this fun annual event visit www.parkinsonalberta.ca/golf-tournament.

2015 Flexxaire Parkinson Step 'n Stride

The 2015 Flexxaire Parkinson Step 'n Stride is only four months away! Sign up yourself or your team today and Step Forward to make a difference at our largest fundraising event of the year! Online registration is open now at www.parkinsonalberta.ca/step-n-stride



2015 SAVE THE DATES

May 9

Red Dress Run

- Edmonton

June 6

Sip, Sample, Support

- Calgary

June 26 & 27

PA MH Support Group Charity Garage Sale -

Medicine Hat

July 16

24th Annual Tulip Golf Tournament

- Calgary

August 9

5th Annual Shoot for Parkinson's

- Edmonton

September 12 & 13

Flexxaire Parkinson Step 'n Stride

- Province-wide

RESEARCH IN ALBERTA SERIES

Parkinson Alberta is proud to support Parkinson disease research wherever it happens, but especially right here in Alberta. Our “Research in Alberta Series”, (which you will find in part here in our quarterly magazine, and in full on our website), is intended to not only showcase Alberta research/researchers; but to promote the diversity and value of research that is taking place on the Parkinson disease front right here in Alberta.

In our third installment of the series, we introduce you to Dr. Jon Doan. Dr. Doan is currently an Associate Professor in the Department of Kinesiology and Physical Education at the University of Lethbridge. Dr. Doan’s research combines mechanical and biological engineering with kinesiology and neuroscience to focus on measuring and interpreting the interaction of human perceptions and actions at work and at play. His current research explores two main topics: 1) perceptual basis of occupational over-loading and soft tissue injury, and 2) exercise therapy and biomedical devices for neurorehabilitation amongst people living with Parkinson disease.

PARKINSON ALBERTA (PA):

Why did you choose to pursue research as it pertains to Parkinson's disease? How did you end up in this field?

DR. JON DOAN (DJD):

I had always planned to go back to school and do my PhD and I had a really great opportunity at Lethbridge to work sort of at the intersection of Kinesiology, Phys Ed and Neuroscience with Dr. Lesley Brown from the kinesiology side and Dr. Ian Wishaw from the neuroscience side. That pair of mentors really enthused me about research with Parkinson disease; they had a wonderful goal and underlying theory which was not to focus on the motor deficits that may exist with Parkinson disease. Instead, we focused on researching the skills it persisted in, what those persistent skills look like, and what they could tell us about roots for neuroprotection, neurotherapy and neuromanagement of Parkinson disease.

PA **What is the current research question you are trying to address and why?**

DJD Our current research focus is in the neuroprotection area and looks at the benefits or the possibility for vigorous exercise as neuroprotection for people living with Parkinson's;

with our specific form of exercise being ice skating. Our interest there is in two parts. There's a big picture and there's a little bit of a smaller picture.

The big picture is that ice skating has biological, psychological and social parts that we think could all benefit people living with Parkinson's. Certainly, the biological part is just the exercise effect on the brain, neural networks and performance. The psychological benefits for exercise we know about are increased emotion, the feelings of exuberance we get from exercise. They are all interesting for us but the social part is the one that we think is uniquely Canadian.

PA **How so?**

DJD So many small towns have an arena as their town center. This is a great opportunity for us to get people living with Parkinson disease back to that town center, maybe with friends, maybe with family, and out for a skate. That is great for a patient who lives in rural Canada who may not have equal access to neurologists or even an exercise therapist or some of the things that we may have in urban Canada. So we thought that the social piece of skating is unique for Canadians and maybe quite beneficial.

PA That makes sense. I'm going to ask what I'm sure some people will be thinking... isn't ice skating dangerous for people with Parkinson's? While I now know that is not the case; it is what I thought the first time I had heard about the research you were doing with skating. Can you talk to that a little bit?

DJD Yes, the skating idea started, or the interest in skating, started for us with the Oprah Winfrey show. Several years ago, Michael J. Fox was on Oprah Winfrey talking about his life with Parkinson's and his many successes pre and post diagnosis. As part of that, he went out for an ice skate with Dr. Oz and he dropped the line, "The amazing thing is that I skate better than I walk."

I'm not a regular Oprah watcher but my mom is and after that episode she called me up and said, "John, did you see Oprah today?" I hadn't had a chance, but I tracked down the episode and agreed with Michael J. Fox, he really did skate better than he walked.

Not long after that we were at a Parkinson Alberta support group in Lethbridge giving a talk about our research (that was taking place) at the time and I mentioned the ice skating piece and said we were interested in seeing if anyone tried ice skating. Two of the young onset patients in the group said that they felt that that would be something they would be interested in. So I got them out in the ice along with a couple undergraduate students from the University of Lethbridge and it was true--they skated better than they walked!

PA Wow! Why do you think that is?

DJD There are some deficits in Parkinson disease that you just can't do in the ice -- the limited arm swing, the small and shuffling steps. If you do those things on the ice, you don't move. So skating and the fact that they are on the ice prompted bigger arm swings, bigger steps and greater locomotion velocity.

When we get participants out on the ice we look at their pre-skating walking, their skating and their post skating walking. We've had people skating through and walking through a doorway to see how the skating affects their freezing. We've done some stick handling

as well as see how bringing in puck handling along with the skating could influence activity and it all looks pretty positive. The part about the skating that we like so much is that there is a lot of transfer to a lot of the activities of daily living. It is balance challenging and requires the arm swings and big big steps; and if we can get people exercising inside those models, we think we're re-networking, redeveloping and/or reinforcing those motor skills that can carry over to walking, improve balance and other activities on regular terrain as well.

PA Were there any unexpected challenges that you've come across while undertaking your research? Still opportunities available for them?

DJD There have been lots of challenges. Certainly, when we mention ice skating and Parkinson's patients together in the same sentence, we get a lot of dubious looks. Parkinson's is well known as having balance challenges, high frequency of falls and of course getting on the ice increases your risk of falls as well. We frequently need to emphasize that Parkinson's isn't exclusively a disease of older people; it affects people across the age ranges. Our research targets young onset patients, moderate patients and people with experience in ice skating. When we think about exercise therapies we need to start developing things for young onset patients as well. It's a problem if they fall through this gap of only having support mechanisms set up for an older patient population.

Dr. Doan's interview can be read in its entirety on our website (www.parkinsonalberta.ca) where he speaks more on skating and PD, access to a program like this, and the importance of doing what you enjoy.

If you do not have access to a computer, please send a self-addressed, stamped envelope to the address below and we will be happy to send you the full transcript.

Parkinson Alberta
#102, 11748 Kingsway
Edmonton, AB T5G 0X5

STEP-BY-STEP GUIDE

to Registering Online

We are only a few months away from our largest fundraising event of the year – the 2015 Flexxaire Parkinson Step 'n Stride! Last year we had more people sign up utilizing our online registration system than ever before! Our online registration system is designed to make your much appreciated fundraising efforts as easy as possible! So whether it is your first time using our online registration, or you just need a refresher, our useful step-by-step guide will help you through the process.

I'm New to the Online Registration Process

If you have never used our easy online registration site before, you will need to set-up an account before you can start fundraising online. The best news, you will only have to complete this step once as our system will remember you each consecutive year and the process is pretty simple!

1. Enter www.parkinsonalberta.ca/step-n-stride into your web browser or visit our webpage and click the Step 'n Stride button; once on the page click on the **REGISTER ONLINE** button under the countdown clock.
2. Under New Participants on the top left side of the new page, click the blue and white **START HERE** button.
3. Click on the Create New Account button located in the centre of the page and follow the prompts. You will be asked to enter the location where you will complete the physical walk. If you choose Calgary or Edmonton, you will be asked if you are participating in the Run or Walk. Once you have made your selection, click the **NEXT** button at the bottom of the page.
4. Read through the waiver and check the small box on the lower left hand side to accept. if you agree with the contents. You must accept the waiver to continue. Select **NEXT**.
5. Registration Type - This page asks you to select how you would like to register for Step 'n Stride
 - a. **REGISTER AS AN INDIVIDUAL** - if you would like to raise funds independently, select and fill in the required information.
 - b. **JOIN A TEAM** - search for the team you would like to join and select by clicking on the team name. Proceed with entering the required information. Please note the team that you are joining must have already registered for 2015 for you to be able to join.
 - c. **CREATE A TEAM** - select that option, name your team and declare your fundraising goal! You will need to answer two permission questions in order to finish creating your team and move to the next step of entering the required information.

Once you have filled out the required information, including creating a Username and Password, click **NEXT**.

6. Regardless of which of the three registration types you chose, you will need to enter your Fundraising Goal, and answer six brief Permission Questions before you are able to click **NEXT** for the final step.
7. Review your information and click **REGISTER NOW!**
8. If you so choose, you can now customize your Personal Fundraising Page. Use this page to add your own personal messages to your supporters and upload photos and videos to your fundraising page. If you prefer to leave this page blank, simply click **CONTINUE REGISTRATION**.

9. Now you are ready to start fundraising! With the help of our online registration system, you can send emails to your family and friends (don't forget to separate email addresses with a semi-colon) or connect using your Facebook account (click the green **GET STARTED** button). You can choose to skip this step at the bottom of the page and come back later.

I'm a Returning Participant, I Just Need a Refresher

1. Enter www.parkinsonalberta.ca/step-n-stride into your web browser or visit our webpage and click the Step 'n Stride button; once on the page click on the **REGISTER ONLINE** button under the countdown clock.

2. Under Returning Participants on the top left side of the new page, enter your Username and Password. Confirm your name and email and click **CONTINUE**. If you have forgotten this information, click on **FORGET YOUR USERNAME OR PASSWORD** and follow the easy prompts to reset your account.

3. Click on Create New Account to register for the 2015 Step 'n Stride and begin to follow the prompts.

Steps five through nine remain the same as a new registrant. If you have any problems or issues during your registration process, please do not hesitate to contact your Regional Parkinson Alberta Office or call toll-free 1-800-561-1911.



NEWS

+ updates

- » PA Red Deer Office is hosting two guest speakers, the first in Red Deer (68 Donlevy Ave) on June 17 at 11:00AM, where a Parkinson disease exercise presentation will be given on strength and balance. The second will take place at 11:00AM on June 24 at the Wolf Creek Community Church in Lacombe. This presentation will be on full body balance and massage therapy. Call PA Red Deer Office for more information 403-346-4463.
- » Our Parkinson's Educational Speaker Series continues in both Edmonton (1st Tuesday of the month) and Medicine Hat (3rd Wednesday of the month). These sessions are designed to provide community members information and education on a variety of topics. More information on this and other programming opportunities at www.parkinsonalberta.ca/in-your-region.
- » Do you have questions about Parkinson Alberta as an organization? John Petryshen, our CEO (and other staff members as required) will be happy to answer your questions about PA's operations, strategic goals, fundraising, administration and Client Services. Simply visit www.parkinsonalberta.ca/ask-the-ceo to submit your question in the form provided.
- » Parkinson Alberta's Annual General Meeting (AGM) will take place at 8:30AM on Saturday, May 23 in Calgary. The AGM will be webcast live in conjunction with the 2015 Regional Hope Conference. Be sure to register by calling 1-800-561-1911 or by emailing info@parkinsonalberta.ca.

Providing Hope Through the Power of Knowledge

With a 40+ year history of Parkinson disease (PD) support services, programming and events in Alberta; collecting resources, documenting events and building a wealth of valuable information to share is a priority for Parkinson Alberta (PA). Each of our six PA Offices has a resource collection accessible to any who wish to utilize this offering. We also offer a PD Resources & Information section on our website, so that regardless of where you live in the province, you have access to quality information.

This year a priority for Parkinson Alberta is to catalogue existing resources and expand our current offerings to include not only printed materials, but audio visual resources, and digital media as well. Though we are still working out the details, our goal is to make all items available to any interested Albertans. At this time we are asking for assistance in this endeavour, if you have items that you would like to donate to Parkinson Alberta:

- materials (books, printed resources) of interest
- photos or newspaper articles of past Parkinson Alberta events
- CDs or DVDs on PD-related topics or events

or have knowledge of the whereabouts of items chronicling the past and present of Parkinson Alberta or ideas for items to be acquired please email [**communications@parkinsonalberta.ca**](mailto:communications@parkinsonalberta.ca)



SUPPORT GROUPS

Please note that support groups run from September through June unless otherwise indicated.

ALBERTA		1-800-561-1911 (toll-free)
TELE-SUPPORT GROUP		
3 rd Thursday of the month	10:00 am – 11:30 am	Advance registration is required to receive call-in instructions & a passcode; call the above number.
CALGARY REGION		Tanya Good/Jennifer Synnott 403-243-9901
AIRDRIE		
3 rd Monday of the month	10:00 am – 11:30 am	Cam Clark Ford – 1001 Highland Park Blvd
CALGARY		
1 st Monday of the month	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
1 st Thursday of the month	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
2 nd Monday of the month	10:00 am – 11:30 am	McDougall United Church – 8516 Athabasca St SE
3 rd Monday of the month Care partners	1:30 pm – 3:30 pm	McDougall United Church – 8516 Athabasca St SE
4 th Monday of the month	1:30 pm – 3:30 pm	PA Calgary Office – 102, 5636 Burbank Cres SE
4 th Monday of the month Young Onset	7:00 pm – 8:30 pm	Hope Lutheran Church – 3527 Boulton Rd NW
COCHRANE		
2 nd Thursday of the month	10:00 am – 11:30 am	St. Andrew's United Church – 128 – 1st St E
NANTON		
4 th Thursday of the month	10:00 am – 11:30 am	St. Cecilia's Catholic Church – 2308 – 19th St
EDMONTON REGION		Chantel Churcher/Susan Skaret 780-425-6400
CAMROSE		
1 st Wednesday of the month	4:30 pm – 6:30 pm	Fire Hall – Mt Pleasant Dr.
EDMONTON		
1 st Wednesday of the month	1:00 pm – 3:00 pm	Rutherford Heights – 949 Rutherford Rd
3 rd Wednesday of the month	7:00 pm – 9:00 pm	PA Edmonton Office – 102, 11748 Kingsway
3 rd Thursday of the month	1:30 pm – 3:30 pm	Providence Renewal Center – 3005 – 119 St
4 th Wednesday of the month Young Onset (under 50 years)	6:30 pm – 8:30 pm	Locations vary – Please call PA Edmonton Office
SHERWOOD PARK		
2 nd Tuesday of the month	1:00 pm – 3:00 pm	Bethel Lutheran Church – 298 Bethel Dr
SPRUCE GROVE		
4 th Thursday of the month	6:30 pm – 8:30 pm	Pioneer Centre – 301 Jespersen Ave
ST. ALBERT		
3 rd Tuesday of the month	1:00 pm – 3:00 pm	St. Albert S55+ Club – 7 Tache St
WESTLOCK		
Last Monday of the month	1:30 pm – 3:30 pm	Room 140, Provincial Bldg – 2, 10003 – 100th St

SUPPORT GROUPS

Please note that support groups run from September through June unless otherwise indicated.

GRANDE PRAIRIE REGION		Kristeva Dowling 780-882-3262
GRANDE PRAIRIE		
2 nd Tuesday of the month	2:00 pm – 4:00 pm	Wildrose Manor – 9358 – 70th Ave
3 rd Monday of the month Care partners	1:00 pm – 2:30 pm	PA Grande Prairie Office – 103, 10901 – 100th St
LETHBRIDGE REGION		Brian Treadwell 403-317-7710
LETHBRIDGE		
3 rd Thursday of the month	2:00 pm – 3:30 pm	Lethbridge Senior Citizens Org. – 500 – 11th St S
RAYMOND		
3 rd Wednesday of the month	2:00 pm – 3:30 pm	Prairie Ridge Centre – 328 Broadway S
TABER		
2 nd Wednesday of the month	2:00pm – 3:00pm	Taber Public Library – 5415 – 50 Ave
LLOYDMINSTER REGION		Judy Harges/Lauren Looy 780-808-5006
LLOYDMINSTER		
4 th Tuesday of the month	2:00 pm – 4:00 pm	Southridge Community Church – 5701 – 41 Street
WAINWRIGHT		
2 nd Tuesday of the month	2:00 pm – 4:00 pm	Provincial Building – 810 – 14th Ave
MEDICINE HAT REGION		Beth Metcalf 403-526-5521
BROOKS		
		Please call PA Medicine Hat Office for more info
MEDICINE HAT		
2 nd Tuesday of the month Care partners	1:00 pm – 3:00 pm	Locations vary – please call PA Medicine Hat Office
2 nd Wednesday of the month Men with PD	12:30 pm – 2:00 pm	Houston Pizza – 26 Strachan Court SE
4 th Tuesday of the month	1:30 pm – 3:30 pm	Kinplex Social Room – 2055 – 21st Ave SE
RED DEER REGION		Moira Cairns/Marilynne Herron 403-346-4463
CASTOR		
4x/year – Next grp May 5	1:30 pm – 3:00 pm	Paintearth Lodge – 4501 – 55 Ave
INNISFAIL		
1 st Wednesday of the month	1:30 pm – 3:30 pm	Church of the Nazarene – 4904 – 48 St
LACOMBE		
4 th Wednesday of the month	1:30 pm – 3:30 pm	Wolf Creek Community Church – 4110 Hwy 12
OLDS		
2 nd Wednesday of the month	1:30 pm – 3:30 pm	Sunrise Village – 5600 Sunrise Cres
RED DEER		
3 rd Wednesday of the month	1:30 pm – 3:30 pm	Davenport Church of Christ – 68 Donlevy St
THREE HILLS		
Every 2 nd month - Next grp June 2	2:00 pm – 4:00 pm	Community Drop In Centre

PD & Constipation:

PREVENTION AND MANAGEMENT

Constipation is a challenge facing many people. Having constipation while living with Parkinson disease (PD) can have a negative impact on your enjoyment of life. Being constipated can be more than just a nuisance. It may interfere with how well your medications are absorbed, making them less effective. Being constipated can make you feel unwell, uncomfortable, irritable, nauseated or lethargic. In severe cases, it can lead to a blockage of the intestine (impaction), making it impossible to pass any stool. In very rare circumstances, impaction requires urgent medical attention. Constipation may also disturb your bladder function and may make you feel that you need to urinate more frequently and urgently.

Arming yourself with information to prevent or manage constipation is an important part of living well and promoting a healthy lifestyle. Just like training for a race, your bowels need to be trained to get into a proper routine. This can take 4-12 weeks, so be patient if you don't see immediate changes! The key is to be consistent in your diet and exercise in order to train your bowels to a new pattern.

Diet

- » Eat fibre-rich foods.
 - These include vegetables (beans, peas, lentils), fruit (prunes, dried fruit, bananas, apples, berries), whole grains, bran and nuts.
- » Increasing fibre-rich foods is the best way to get more fibre; however, you can supplement your diet with bulk formers like Metamucil, Benefibre, Prodiem or fibre pills.
- » Use "laxative jam"
 - 1 cup chopped pitted prunes
 - 1 cup chopped dates
 - 1 cup water
 - Boil together until thick
 - Your "jam" is now ready to use and should be stored in the refrigerator

Fluid Intake

- » Drinking plenty of fluids (8 - 10 glasses) throughout the day is important. If you have increased your fibre, you need fluid to help it work. Any fluid will work – water, soup, tea, fruit juice. Remember, fizzy drinks may make you feel bloated and, for some people, milk may increase constipation.
- » Avoid caffeine and alcohol which act as diuretics or "water pills". This can make constipation worse.
- » Start the day with a warm drink. This will help get the bowels moving.

Exercise

Exercise helps to stimulate the bowels for proper action. Aim for at least 15 - 30 minutes of exercise a day.

PD is in your life and constipation can add to the challenge of living well. If, despite all your efforts, constipation remains a challenge, ask for a referral to a dietician. Meal plans and strategies from a dietician may be very helpful.



IMPORTANT!

If you are increasing the fibre in your diet, be sure to introduce it gradually and always make sure you are drinking enough fluids or you will become more constipated!



Last Look

WHY YOU WALK VIDEO CHALLENGE

On September 12th and 13th at locations across the province over 1500 Walkers will gather to raise funds and hope for people affected by Parkinson disease. Each of our Walkers has a unique story to share; and with the 2015 Flexxair Parkinson Step 'n Stride right around the corner, it's the perfect time for you to tell yours.

Create a short video (approximately 15 - 90 seconds in length) sharing why you, your family, and/or your team participate in Step 'n Stride. Be heartfelt. Be funny. Keep it simple, or go over-the-top! Just let us know "Why You Walk". It can be easily done with a cell phone or webcam.

We'll share all the videos we receive on our website, YouTube Channel, Facebook, Twitter and Google+ accounts.

**Don't forget to use the hashtags
#StepNStride and #WhyIWalk**

Video submissions will be used for promotional purposes by Parkinson Alberta. Videos will be posted on Parkinson Alberta's website and YouTube Channel and videos may appear in other promotional pieces including, but not limited to, social media forums (Facebook, Twitter, etc), e-communications and presentations. By submitting a video, you consent to its promotional use by Parkinson Alberta. Videos will become property of Parkinson Alberta.

Video submissions will be accepted by email to communications@parkinsonalberta.ca between now and September 9, 2015.

Renew or become a member today via the form on the opposing page or by calling toll-free 1-800-561-1911. You can also renew/sign up through our website at www.parkinsonalberta.ca/become-a-member.

Parkinson

Alberta



FLEXXAIRE

PARKINSON



September 12 & 13, 2015

Thank you supporters

Parkinson Alberta would like to thank the following sponsors for their commitment to ensuring that Albertans affected by Parkinson disease receive the quality and level of support and service necessary to live better with PD.

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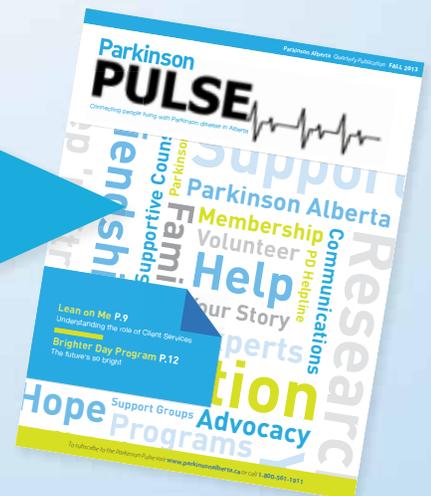


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Would you like to see your company ad in the **Parkinson Pulse**?

Advertising rates and opportunities are available.



Contact:
Brandi La Bonte
communications@parkinsonalberta.ca
780-425-6400 ext 225



2015 Regional Hope Conference

Saturday, May 23, 2015
7 locations across the province

Calgary – Edmonton – Grande Prairie – Lethbridge – Lloydminster – Medicine Hat – Red Deer

Featuring Keynote Speaker:
Dr. Becky Farley



For more information or to register visit:
www.parkinsonalberta.ca/2015-regional-hope-conference or call 1-800-561-1911