September 9
- Calgary
  South Glenmore Park
- Edmonton
  Rundle Park, ACT Centre
- Grande Prairie
  Muskoseepi Park
- Lethbridge
  Indian Battle Park
- Lloydminster
  Bud Miller Park

September 10
- Bonnyville
  Little Leap Park
- Camrose
  Mirror Lake
- Cochrane
  Mitford Park
- Medicine Hat
  Crescent Heights High School
- Red Deer
  Festival Hall

Details available on our website now!

Online Registration is now OPEN!
www.parkinsonalberta.ca/stepnstride
Parkinson Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.

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Please visit our website: www.parkinsonalberta.ca/aboutus to view our staff and board list.

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

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

Advertising rates and opportunities are available.

Contact:
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From the Desk of

THE CEO

Parkinson Alberta has a four-pillared approach to Parkinson disease...support, education, advocacy, and research. In this issue of the Pulse we focus, for the most part, on the latter - research.

For millennia people have been living with and families have been affected by a Parkinson disease diagnosis. It is only since the 1960s however, that significant strides began to take place to help alleviate the symptoms and improve quality of life.

Levodopa, dopamine agonists, deep brain stimulation, Duodopa, exercise and other complementary therapies are just some of the many positive and impactful outcomes of Parkinson’s research.

The good news is that, despite the fact that there is still no known cause or cure, Parkinson’s research has come a long way with many Parkinson’s symptoms now (within reason and varying as the disease progresses) being controlled and/or reduced in severity. The unfortunate news is that without research the outlook is still disheartening. Without research Parkinson disease will continue to steal pieces from the lives of individuals and families. Independence, abilities, cognition, and even familiar smiles will be stolen by this devastating disease.

Research is the key to a better and brighter future in Parkinson disease. Research, of course, into a cause and cure; but also into aspects that will help people live well with the disease right now. New medications, new ways to deliver treatment, new understanding of non-motor symptoms like cognitive function and depression, or new ways to approach life with Parkinson disease are just a portion of the research that is being undertaken.

Through our Champions of Hope Research Campaign (page 6) we aim to illuminate, innovate and inspire.

Illuminate not only what is taking place in Parkinson’s research, but the challenges that inevitably come with taking on the science behind Parkinson’s. For example, did you know it costs an estimated $1-2 billion to develop a new drug and that the process can take over a decade? Or that the failure rate of this drug development process is approximately 95%?

Innovate by providing funding to the researchers and bright young minds of tomorrow so that they can continue to work towards unlocking the mysteries of Parkinson disease and finding new solutions to living well with this disease.

Innovation also comes as research progresses from animal models (if applicable) to human trials; researchers worldwide, and here in Alberta, conduct clinical studies on various aspects of Parkinson disease. However, studies can only be completed if people volunteer to participate in them. By participating in clinical studies, both people living with Parkinson disease and those without can help make an impact on improving the quality of life for ALL people with Parkinson’s. Many of our own participate in clinical studies, you can read one of their stories on page 4.

Inspire people living with and affected by Parkinson disease as well as Albertans as a whole to get involved in creating a brighter future in this disease.

You will find inspiration at our 2017 Hope Conference where many of our speakers will present either on research itself, or on topics that have a positive impact on life with Parkinson disease as a result of research. Topics like exercise, speech and swallowing issues, driving and nutrition, to name a few. Join us on May 27 at this exciting, informative and engaging event; more information is listed on page 10.

Another great opportunity for inspiration is our 2017 Flexxaire Parkinson Step ‘n Stride™ (page 16). This uplifting and energizing event sees over 1500 people gather across the province to raise the profile of Parkinson disease while also raising critical funds for support and research!

Illuminate. Innovate. Inspire. I encourage you to help us make a difference in Parkinson disease for today and tomorrow.

John Petryshen, CEO
Parkinson Alberta
I learned about the Ambulosono Project from Susan Loewen, my Physical Therapist at the Movement Disorders Program in Edmonton. She encouraged me to get involved. I feel that it is important to be involved in activities and initiatives related to Parkinson’s so I applied to be part of the research project.

The Ambulosono research project originated in Calgary, but I worked with Dr. Camicioli and Jacqueline Byrt, the Study Coordinator in Edmonton.

To participate in the research I had to make three visits to Edmonton from Lloydminster at six week intervals. At the first meeting I was tested to establish base lines for cognitive function and balance. I also learned how to use the “walking equipment” including how to download information through the internet. The equipment consisted of an ipod that attached to my leg to measure stride length and head phones so I could hear the music being played by the ipod. Upon returning home I was required to walk a minimum of 30 minutes at least three times per week for six weeks. This established a base line for my stride length.

After the second meeting and testing, which took about two hours, the ipod program was modified to play music only when my stride length met or exceeded the expectation established by the researchers. If my stride length became too short, the music stopped playing. As the program progressed, information was downloaded to Edmonton and adjustments were made to the required step length to keep the music playing. The cue of the music certainly kept me aware of how I was walking and my stride length.

The individual cognitive and balance results were not shared, so I do not know what impact the program had on those items. However, the program was long enough to improve my stride length, heel strike and arm swing. These improvements have carried over for nearly two years.

The program was so successful on a personal level that I wanted to purchase the equipment to continue to reap the benefits. I was disappointed when I was unable to make this happen.

However, I feel my involvement was a positive experience that has helped my quality of life. I like to think that my participation in a research study could help someone with Parkinson’s – even in a small way. Ambulosono, being a home-based study, allows people who do not live in the larger centres to be involved and contribute to research. I would encourage anyone who wants to be involved in the fight with Parkinson’s or who is interested in helping themselves and others to volunteer for a research project.
Question: I am experiencing pain in my lower back and my legs seem weak and shaky, though not all the time. This is especially happening in the morning when I get up. I do go to tai chi 2-3 times a week and even there I experience the same pain. Is pain part of PD?

Answer: The short answer is yes, pain can be part of PD. This can occur in several situations. First, if a person is on levodopa, and the effects of the last dose have worn off (such as in the morning before the first morning dose) there can be quite a bit of slowness and stiffness in the legs. This can produce an aching discomfort associated with a feeling of weakness.

The second type also typically occurs in the morning, or during the night, when the evening dose of levodopa has worn off, and results in a "Charlie horse" type of cramping in the legs. This can be very painful. The third type of pain can occur during the day as a "wearing off" phenomenon, when the pain comes along with the stiffness and slowness. All three types of pain can be improved by appropriate adjustment of levodopa, or other PD medications.

However, there are a number of other problems that can cause low back pain and weakness of the legs, such as a prolapsed disc, or arthritis, and a full evaluation by a physician should be done to make sure that there are no other factors contributing to the back pain.

Question: I wonder about the benefit of medical marijuana in advanced stages of the illness both on mobility but also pain and better sleep. Are there specialist here in Edmonton who help one learn how to administer and what type of options are available?

Answer: There is a lot of interest in medical marijuana these days, but it should be recognized that there is very little research to support its use in most conditions, including Parkinson disease. It can be helpful in treating chronic pain, and anxiety in some cases. It should be recognized that regular use can have side effects such as depression and memory loss. At this time, marijuana cannot be recommended as a standard treatment for PD. If someone is interested in finding out more about whether it could help their symptoms, there are several special clinics that prescribe marijuana in Alberta that he or she can be referred to by a physician.
For more than 50 years, research in Parkinson disease (worldwide) has been instrumental in finding new treatments to address symptoms of Parkinson’s, understand pathophysiology, and improve quality of life. However, research for and into Parkinson disease has long been undervalued, and currently there are limited funds that support research for Parkinson disease and other movement disorders.

At Parkinson Alberta, our mandate is to work with those living with and affected by Parkinson disease to provide a variety of support programs and services, as well as funding research to inspire hope. To that end, Parkinson Alberta is dedicated to making significant investments to support Parkinson’s research and innovation with leading universities in Alberta.

We propose to do this by embarking on the largest fundraising initiative by a Parkinson organization in Canadian history to support research both locally and nationally via our Champions of Hope Research Campaign.

The Champions of Hope Research Campaign is led by a committee of individuals who want to raise funds to help the Parkinson’s research community in Alberta. Parkinson Alberta is positioned to lead this movement, through leadership and commitment to this endeavor. Our Campaign is led by world renowned investigator, Dr. Suchowersky, Chair of Research and Parkinson Alberta Board Member and Champions of Hope Research Campaign Chair, Bob Fisher the first significant donor to invest in our campaign. They will be the “faces” of the Campaign and driving force behind fundraising initiatives.

Our Champions of Hope Research Campaign is about enhancing and increasing the capacity for Parkinson disease research by providing funds that support current researchers as well as today’s bright young minds through University/Institute led research.

By taking this approach we can ensure the further study of a variety of Parkinson’s related issues including, but not limited to:

- Improving treatment of:
  - motor symptoms, such as gait and balance as well as studying new treatments
  - non-motor symptoms such as pain, anxiety, sleep, cognitive decline and fatigue
  - psychiatric symptoms
- A more complete understanding of:
  - environmental and genetics factors as a cause of Parkinson disease
  - caregiver impact, physical wellbeing and stress
  - social and psychosocial impact and community awareness
- Using exercise and other allied health treatments to improve quality of life
- Enhancing end of life issues
- Improving use of neuroimaging to improve diagnosis and enhance therapies

Not only do we need to enhance and encourage research in Parkinson disease, but other related neurological conditions, for which there is very limited funding, as well. These similar conditions may help with the overall understanding and treatment of these groups of disorders. These include: Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Cortico-Basal Ganglionic Degeneration (CBD), and Dementia with Lewy Bodies.

Parkinson Alberta is prepared to lead this exciting program in order to enhance research that will impact so many lives in our province as well as nationally and internationally. Parkinson disease is a significant contributor to the cost of health care in our province. When we invest in research we are helping not just people living and/or affected by Parkinson’s but also our health care system by way of improved care, better quality of life, and a decrease in the use of health care resources. In this way, we will lead the way in decreasing health care spending while at the same time providing inspiration and hope to many.

It is with confidence and forward thinking that we invite you to join the cause and make a significant impact on the lives of 10,000 Albertans, and their families.
Due to a scheduling conflict, PA Red Deer's 2017 Flexxaire Parkinson Step 'n Stride™ will take place on Sunday, September 10 instead of the usual Saturday date. The location and times remain the same.

Do you live in a region without a physical Support Group? Or maybe you prefer to take part in a Support Group from the comfort of your own home? We invite you to take part in our year-round, monthly Tele-Support Group! This group takes place via conference call on the third Thursday of each month from 10-11AM. Each month features a speaker discussing different aspects of Parkinson disease. Call 1-800-561-1911 for more information or to register.

Be sure to connect with your Regional Client Services Coordinators to find out what Support Groups and program opportunities are available to you this summer!
In our Winter 2015 issue we introduced readers to Dr. Oksana Suchowersky. In this issue we reach out to Dr. Suchowersky again for an update and to ask her a few more questions in regards to Parkinson disease research. Dr. Suchowersky’s work allows Alberta to remain at the forefront of Parkinson’s research and treatment.

PARKINSON ALBERTA (PA):
You’ve been involved in Parkinson disease treatment and research for over 30 years. What would be some of the highlights of your career?

Dr. Oksana Suchowersky (DOS):
Certainly, my highlights are being involved with patients and being able to treat patients. Another highlight is the increase in the number of medications being made available and being involved in the research that has brought some of those medications to market.

Being involved with the Parkinson Study Group, which is a large international collaboration of clinicians and researchers looking at Parkinson disease, has been rewarding. It’s based in Canada and the US. They’re all involved in improving treatment and finding a cure for Parkinson disease. It’s been going on since 1987 and we’ve been doing multiple studies over the years to address those questions.

PA You have a background in genetics. How new is the theory that PD has a genetic component?

DOS When I started my practice some 30 years ago it was said that Parkinson’s is not genetic and everyone was looking for environmental causes. It has really only been over the past 10 or 20 years that it’s been increasingly recognized that there is a genetic component. In young onset Parkinson’s there is a very strong genetic component but even in older people, we now understand that there is probably a genetic predisposition and then the condition environmental conditions that you get Parkinson’s. The younger you are, the stronger the genetic influence, the older you are it’s probably a combination of genetics and environmental factors. It’s only been in the past 10 years or so that people have found the genes that are responsible so we now know the 20 genes that are involved in either minor or major factors resulting in Parkinson’s.

PA Are the clinical trials of Duodopa still underway? Is there anything new to report there?

DOS Yes, multiple trials are still underway. In Edmonton, we were the first in Canada to start a patient on Duodopa, which is providing levodopa directly into the intestine so it’s better-absorbed. Since then we’ve brought Duodopa into practice in Alberta and now any patient can have access to Duodopa. I’m still continuing research into Duodopa to see whether it treats motor symptoms vs non motor symptoms, what side effects people are having, and so on. There are a variety of ongoing research trials, although the treatment is available as a clinical treatment now for anybody with advanced Parkinson’s.

PA You’ve spoken about neuroprotective therapy. Are there currently any clinical trials for that? Are there new compounds that can slow the progression of PD?

DOS We have a trial underway through the Parkinson Study Group, called STEADY-PD which is using a drug that we think can slow down the progression of Parkinson’s. We also are looking at the potential of drugs that can decrease inflammation.
One of the interesting theories is that as the cells are involved in the pathological process, a lot of inflammation is occurring. If we can decrease inflammation in the brain, it may decrease progression of Parkinson’s. Trials will be coming out related to anti-inflammatories.

Another area we’re always interested in is exercise. There have been studies to show that if you exercise regularly, you may decrease your risk of getting Parkinson’s and you may slow down the progression of the disease.

**PA** What other research are you anticipating the results of?

**DOS** One of the other interesting things is how you can predict if someone is developing Parkinson’s. We now know that changes in the brain related to Parkinson’s may start in the nose or may start in the gut, and then gradually spread to the brain. People may be developing a pre-Parkinson’s, if you will, for about 10 years before they develop the motor symptoms of Parkinson’s.

I think an important area of research is trying to predict who is going to get Parkinson’s and intervene at that level. Because, of course, once you get Parkinson’s, the pathology is already developed in the brain, so how can we stop it from developing into Parkinson’s?

**PA** Just yesterday, we had a client at our Calgary Office tell a group of clients, “Canada and specifically Alberta is the best place in the world to have Parkinson disease.” It’s an interesting way to put it, but would you agree with that statement?

**DOS** I really appreciate the compliment and I think that we do a very good job in Alberta of treating Parkinson’s. In both Calgary and Edmonton we have multidisciplinary clinics that look after people with Parkinson’s and I think that’s very important. They have the benefit of not only neurologists, but nurses, occupational therapists, physiotherapists, and social workers. Things like exercise programs that provide comprehensive, multi-specialty care for people with Parkinson’s, for example. We may call in geriatricians or urologists, or other specialists to come deal with the multiple facets of the disease.

**PA** How important is it to have people with Parkinson’s participate in clinical trials for research?

**DOS** It’s extremely important because that’s the only way we’re going to find out about what causes it, how to prevent it, and how to treat it better. Without research, we’re going to be stagnant.
GET YOUR "LIVING WELL TOOLBOX" READY AND JOIN US ON SATURDAY, MAY 27 FOR THE 2017 HOPE CONFERENCE!

The theme for this year's event is "Your Tools for Living Well with Parkinson's"! Taking place in all seven of our regions across the province this one-day conference features speakers addressing Parkinson’s issues such as mental health, pain, research, new treatments, grief and more! Condensed itineraries are listed below – the full day’s schedule and detailed information on the presentations are available via our Regional Client Services Coordinators or on our website – www.parkinsonalberta.ca/hopeconference.

Don’t miss this incredible opportunity to gather together with the Parkinson’s community for a chance to gather new insights and information, ask questions of experts, socialize, and share your struggles and triumphs with others who truly understand what it means to be affected by Parkinson disease.
Join us at Thorncliffe Greenview Community Association for our Hope Conference where the day’s speakers will include:

- Dr. Aaron Mackie – PD & Mental Health
- Evelyn Chung, BSc, RD – Parkinson’s and Nutrition
- Shannon MacKinnon, MSW, RD – In Sickness & Health – Intimacy & Parkinson’s
- Dr. Bonnie Dobbs – Driving and Parkinson’s
- Duodopa Panel with Eric Tse, Duodopa Nurse and clients who have undergone the procedure
- Ask the Experts Q&A Session

Cost is $35 for Members, $45 for Non-Members. For more information or to register call 403-243-9901.

Central Lion’s Recreation Centre is the location for our Hope Conference in Edmonton. The day includes opportunities to take in the following presentations:

- Dr. Oksana Suchowersky – Research: Changing the Future of Parkinson’s
- Ask the Experts Q&A Session
- Breakout Sessions
  - Dr. Fang Ba – Medical Management of PD
  - Dr. Jorge Perez-Parada – Depression, Anxiety & Apathy
  - Charlene Heavener, RN & Susan Loewen, PT – WELL (We Embrace Living Life)
  - Genise Termain, RN & Karen Toore, RN – Treatment of Advanced PD: Duodopa vs DBS
- Mary Ellen Plumite, RN & Jan Wilson, OT – Intimacy & Parkinson’s

Cost is $35 for Members, $45 for Non-Members. For more information or to register call 780-425-6400.

The 2017 Hope Conference will take place at Elk’s Hall and will include opportunities the following presentations:

- Lindi Vanderschaaf, SLP – Swallowing Issues & PD
- Kelsi McInnes, MT – Music & Wellness
- Rosanna Clark, PT & Sailaja Bayapaneni, PT – Get Moving! Exercise Essentials for PD

Cost is $25 for Members, $35 for Non-Members. For more information or to register call 780-882-6640.

Join us at the LSCO for the 2017 Hope Conference and enjoy presentations from:


Don’t miss this incredible opportunity to gather together with the Parkinson’s community for a chance to gather new insights and information, ask questions of experts, socialize, and share your struggles and triumphs with others who truly understand what it means to be affected by Parkinson disease.

Cost is $25 for Members, $35 for Non-Members. For more information or to register call 403-243-9901.

Southridge Community Church will be the location for the 2017 Hope Conference; the day includes presentations from the following:

- Dr. Wayne Martin – Parkinson Disease Today & Tomorrow
- Q&A with Dr. Martin
- Judy Hardes – Finding Hope (two part presentation)
- Wellness Fair

Cost is $25 for Members, $35 for Non-Members. For more information or to register call 780-808-5006.

Hope Conference will take place at Holiday Inn Express & Suites and include the following speakers:

- Tanis Robinson – Sustaining Wellness with PD in Rural Communities
- Lorna Scott – Let Your Heart Guide the Way (two part presentation)
- Dr. Ranveet Grewal – PD & Vision

Cost is $25 for Members, $35 for Non-Members. For more information or to register call 403-526-5521.

Join us at Davenport Church of Christ for our Hope Conference where the day’s speakers will include:

- Cari Cooke, BScPT - Get Moving! Exercise Essentials for PD
- Meredith Kramer, RD – Food for Thought...Nutrition & PD
- Cassello Watson, SLP – Speech, Swallowing Treatments for PD

Cost is $25 for Members, $35 for Non-Members. For more information or to register call 403-436-4463.
PARKINSON ALBERTA (PA):
In our last interview, you spoke a lot about hope and specifically, the evolution of hope. Is it difficult to give people with Parkinson's hope when they're having off days or when their symptoms progress?

Dr. Janis Miyasaki (DJM):
There are many issues surrounding hope in Parkinson's, one is the pre-morbid personality. Some people are just naturally optimistic people, but that may change when they develop Parkinson's because there are neurochemical changes that can affect mood and motivation. However in my 25 years of experience there are people who maintain a very optimistic outlook. These are people who are able to take great meaning in day-to-day things that occur.

For example, one of my patients in Toronto was in a wheelchair and had to have an ostomy bag because she got an ischemic bowel as a complication of Parkinson's. She was quite cognitively impaired and was requiring full-time care; and yet every time I saw her, when I asked how she was, she would say, "I'm just great." She always had something good to tell me about what had happened in the last three to four months. Her family was also good at incorporating activities to help her feel hopeful. They arranged afternoon tea with some of her former students. They would organize things that were social and engaging for her. They were also fortunate enough to have around-the-clock care.

Even in the face of great disability and suffering, there can be hope. There can be meaning. I really believe that. However, if a patient defines a "good day" as going to work, putting in a full day and then doing all the activities around the house, they may not be able to reach that again. And, with Parkinson's, there will come a time when they can't reach that. Rather than thinking there is a time to reflect and change priorities, they may just say, "I am useless because I can't work."

PA How would that affect disease progression?

DJM I think that when you develop that negative view, it becomes hard to understand why you should do anything that improves your condition. As we are now much more aware, exercise and socialization are very important in Parkinson's. If you feel that this is a relentlessly progressive illness that nothing can stop, then why would you put in the effort to go and do those things? There are very few people who say, "Yay! Exercise!" If we called it something else, maybe people would want to do it more.

PA We almost need a euphemism for exercise.

DJM We came up with a term -- "self-managed care". Instead of something that you have to go and do, it's a self-managed activity. Patients can say, "I am going to manage my illness by doing this."

There is research which shows that people who exercised frequently around the time of Parkinson's diagnosis, those people did the best. The next best were the people who started exercising in the first year after diagnosis. They did better than the people who started exercising two years later. Even some exercise is better than none. You have to feel there is a purpose to it. You have to feel that there is hope that you are affecting change. That you feel some self-agency.

Many people who develop an illness become so medicalized that they lose that self-agency. I mean that "I have control over what happens". Control over
how they respond to circumstances. They can choose their own path whether it's negative or positive.

I think that the medical system and many people's approach to disease is in many ways passive. "I have a diagnosis, give me a pill" or "I have a diagnosis, give me surgery. Replace what is not right". Rather than "What is there that I can do that will improve my quality of life?"

**PA** How does that relate to your work with advanced care planning?

**DJM** That is an opportunity for people to make choices and have discussions with physicians or health care providers who know their condition very well, rather than lawyers. I'm surprised at the number of people who actually do their advanced care planning document with a lawyer. Although it is a legal document, it isn't really something that a lawyer can really counsel you about. For example, a lawyer cannot tell you what will happen if you have early-stage Parkinson's and you go to the ICU versus if you have Parkinson's in later stages and you have dementia and you go to the ICU. Yet that information is really important to the decision you make to go to the ICU or not.

**PA** So would you recommend having a physician or neurologist in those discussions in addition to a lawyer?

**DJM** You don't need the lawyer (for that particular discussion). What's amazing is Alberta has a very well-developed system called the Goals of Care, also known as the "greensleeve" because it goes into a green plastic sleeve that patients take everywhere with them. It very clearly outlines the levels of care because often documents have things like, "if I'm in the ICU and there is no hope of recovery, then I want to be unplugged". I know it sounds specific, but to a physician it's very non-specific. What does recovery mean? Does it mean recovery to the previous state? Recovery to recognizing family? Recovery to being alive? Or does it mean something else?

The Goals of Care document is very complicated and a physician is needed to complete it but it does go through the levels of intensive care treatment, medical treatment, as well as comfort care.

To have those conversations in an emergency department is not good because that's a time when everyone is emotionally charged, the situation is very stressful. The patient may have been waiting for many hours and there's been an acute change in health. As opposed to having that discussion in a doctor's office in a fairly stable state of health and discussing with family prior to making a decision.

Having a Goals of Care form completed with family should be done for anyone after the age of consent. Things can happen that we can't predict, even for a 19 year old. What are the appropriate goals of care for a 19 year old who is in perfect health compared to a 70 year old who has a chronic neurologic problem? They're two different things and the outcomes are different.

**PA** A 19 year old would never think about that but obviously it's important to consider.

**DJM** I think that having the Goals of Care completed is part of things we should be doing. We should be talking to our families about. To have it in an informed way is also very important. I've also read some documents that people download from the internet and they are often not specific and therefore can't help direct care. That's unfortunate because the family feels bound by those written words, even if they're not in the best interest of the person.

The hardest thing for families in hospital is to be sure they're doing what the patient wants or would have wanted. Many people know what might be in the person's best interest, but to be sure you're doing what the person wanted is really hard. It's hard to put aside one's own feelings of wanting the person there no matter what versus what that person wanted. To be selfless like that is hard and it's a terrible position for a family to be in if they haven't had the discussion before.

**PA** You've mentioned that society has made death a "disease". Obviously it's something that's difficult to talk about. With so many "baby boomers" reaching advanced age do you find that's changing at all?
I think a lot of people, as they get older, want to talk about it. There are always going to be some people who never want to talk about it but there are quite a few people who want to.

There was a research study that looked at family doctor appointments with elderly people. In the study, the topic of death was hinted at several times by the patient and ignored by the physician. That may stem from the fact that doctors are human too. They get attached to their patients and some of them don’t want to think about or talk about these things. Or they’re concerned that people will get angry. Also, for many of them their only discussion or encounter with advanced care planning or goals of care is in a hospital setting when people are very emotional as opposed to in an ambulatory setting. They can address the likelihood of patients returning to their previous level of health.

The chances of returning to a previous level of health from the ICU are poor, even for people in their thirties who were in good health prior to going in. Most of them report fatigue, not being able to go back to work, they have cognitive problems, and mood problems. Going to the ICU is not a benign thing and most people don’t realize that. On television it looks so clean, tidy, and peaceful. But if you talk to anyone whose family member has been in the ICU, they’ll tell you that the care is excellent but it’s a very traumatic time. Most often patients are sedated, they can develop complications. It can be noisy, bright, and disconnected. It’s not an easy thing to go through for any person. When ICU stays are brief (a few days) people generally do well. When they’re long and when one complication leads to another, the outcome is generally not as good.

Our centre has completely moved to the electronic health care record. Our patients’ records are available on the University of Alberta system. This means that any family practice clinic or physician that is connected can access them through AHS. The reason why this is important is, people can look at the notes. They can look and say, “Oh, you were seen by Dr. Miyasaki last month. Let’s see what she said,” and they can actually look it up. They can see everything that we do.

Our clinic has also standardized a lot of assessments for our patients so they’re more consistently getting an assessment of both cognitive status and non-motor symptoms every year. Yet we’re still maintaining our patient volumes of over 5,000 patient visits a year. In addition, we’re starting a new surgical screening clinic in June and that will be staffed by Dr. Fang Ba, who is the neurology lead for the surgical program and movement disorders, and myself and we’ll be seeing approximately 12 patients a month to screen them for eligibility for surgical interventions in movement disorders.

Would that include procedures like deep brain stimulation (DBS)?

It could be anything from the Gamma knife, lesions, or deep brain stimulation and includes all the different varieties of patients we see. Although the movement disorder clinic is dominated by Parkinson disease; in fact, we care for a whole group of patients on a long-term basis.

Our movement disorder clinic is quite varied in terms of the patients, procedures, and modalities that we can use to assist them. We’re taking full advantage of that. We’ve also had an occupational therapist join our team and we’re looking forward to her contributions to our patients’ well-being.

We’re really starting to do a lot more investigator-driven studies. There are industry-sponsored studies, which are generally surrounding medication. Then there are investigator-driven studies and these are studies that ask questions that are of interest to the investigator or in our case our neurologists or our neurosurgeon, Dr. Tejas Sankar. We have questions that may never be of interest to a drug company but are very interesting to us because they impact our patients and because the clinical care of our patients is informing our research, which is that crucial link. For example, the Hope Study involves doing a positive psychology study to see if giving patients positive psychology-based group therapy in the early stages can help them be more positive and therefore be more engaged in their healthcare.
PA: Is that an ongoing study?

DJM: It’s halfway done. In the fall we’ll have another cohort of patients and I have to give many kudos to Susan Skaret at Parkinson Alberta in Edmonton because she’s been a great supporter of sending patients to us who might be eligible.

I’m the principal investigator for the first large-scale randomized controlled study of palliative care in an ambulatory setting given by movement neurologists and that is halfway through also. This is really for anyone who has unmet symptomatic needs, who has existential distress, or caregiver burnout and has Parkinson’s or Parkinson Plus and they can be recruited into the study, which lasts a year.

Finally, we were just added to the National Parkinson Foundation “Parkinson Outcomes Project”, which is a cohort currently of over 10,000 people with Parkinson’s around the world who are being followed on an annual basis to look at standardized measures and give quality information back to the site but also to inform the neurology field in general about what things are important for people with Parkinson’s.

PA: What do people not know about your clinic?

DJM: Often people are surprised that our centre is so big and that it’s so busy. So my job is to make that much more known. Our clinical nurse at the Kaye Edmonton clinic was selected for the National Parkinson Foundation mentor program so she’ll learn some of the things going on at other centres. That will help other people see that our centre is busy, vibrant, and that we have many disciplines that many other sites in Canada do not have. We are really fortunate because that’s all been possible through support of Parkinson Alberta and AHS. They’ve been really supportive of our clinic.

PA: How important is it for people to participate in research?

DJM: Participation in research is an important aspect of hope. I’ve been doing research in Parkinson’s since 1992. When people participate in research and they say, "I’m doing this because it may not help me, but it will help the people who come behind me," that’s an altruistic thing and it’s important for us all to have some feelings of selflessness. Also, to believe that what you’re participating in will help people who come behind you, that’s hopeful. It’s empowering for people to participate in research.

Studies have shown that people who participate in research are better informed about their illness, they feel that they’re more able to ask questions and advocate for their healthcare, that they feel that they have up to date information. Often people realize we’re constantly doing research and it helps them feel like they’re part of the progress and that their physicians are part of the progress too.

I think that once patients participate in one study, they generally have a good experience and they want to participate in more. Some of them, as soon as they finish one study, say, "Is there another one I can do?" or some say, "Is there anything else? Do you have another study I can do?" during the study. They find it quite enjoyable. We’re really grateful that our patients have been very positive about it.
Incredible things happen when we engage as a community to support those we love living with and affected by Parkinson disease. From sons and daughters, to grandkids and neighbors, to coworkers, health professionals, community partners and of course, Parkinson Alberta Staff, the more we engage with each other, the more we accomplish in the fight to live well with Parkinson’s!

Join us at our 5th Annual Flexxaire Parkinson Step ‘n Stride™ which promises to be our biggest to date! Registration is open for this is a fun, family oriented event that raises vital funds for Parkinson disease support services, education, advocacy, and research.

### SATURDAY, SEPTEMBER 9
- Calgary
- Edmonton
- Grande Prairie
- Lethbridge
- Lloydminster

### SUNDAY, SEPTEMBER 10
- Bonnyville
- Camrose
- Cochrane
- Medicine Hat
- Red Deer

The best way to ramp up the fun, crank up the excitement, and generate pledges is to mobilize your own team! Teams come in all shapes and sizes and can be made up of your family, friends and/or coworkers. Show your kids and grandkids what a community looks like by letting them in on the action too! Don’t forget to showcase your team by sharing your photo on Facebook, Twitter and Instagram and tagging us at #ParkinsonPosse.

**WEAR YOUR SUPPORT!**

Be among the first to own and wear our NEW “I Love Someone with Parkinson’s” t-shirt!

The 100% soft, white cotton t-shirt is available in a unisex cut in both adult sizes S-2XL) and child sizes (S-L).

T-shirts are $20 and will be made available for pick up only at a Regional Office or Walk event. T-shirts can be ordered via our website www.parkinsonalberta.ca/stepnstride or by contacting your Parkinson Alberta Regional Office.

Deadline for placing your order is August 4, 2017.
## SUPPORT GROUPS

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

### ALBERTA

**TELE-SUPPORT GROUP**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>3rd Thursday of the month</td>
<td>10:00 am – 11:00 am</td>
<td>Advance registration is required to receive call-in instructions &amp; a passcode; call the above number.</td>
</tr>
</tbody>
</table>

### CALGARY REGION

**AIRDRIE**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>3rd Monday of the month</td>
<td>10:00 am – 11:30 am</td>
<td>Cam Clark Ford – 1001 Highland Park Blvd</td>
</tr>
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</table>

**CALGARY**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Monday of the month</td>
<td>10:00 am – 12:00 pm</td>
<td>Hope Lutheran Church – 3527 Boulton Rd NW</td>
</tr>
<tr>
<td>1st Thursday of the month</td>
<td>10:00 am – 11:30 am</td>
<td>Hope Lutheran Church – 3527 Boulton Rd NW</td>
</tr>
<tr>
<td>2nd Monday of the month</td>
<td>10:00 am – 11:30 am</td>
<td>McDougall United Church – 8516 Athabasca St SE</td>
</tr>
<tr>
<td>3rd Monday of the month - Care Partners</td>
<td>1:30 pm – 3:00 pm</td>
<td>PA Calgary Office – 102, 5636 Burbank Cres SE</td>
</tr>
<tr>
<td>4th Monday of the month</td>
<td>10:00 am – 11:30 am</td>
<td>McDougall United Church – 8516 Athabasca St SE</td>
</tr>
<tr>
<td>4th Monday of the month - Young Onset</td>
<td>7:00 pm – 9:00 pm</td>
<td>Hope Lutheran Church – 3527 Boulton Rd NW</td>
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**COCHRANE**

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<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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<tbody>
<tr>
<td>2nd Thursday of the month</td>
<td>10:00 am – 11:30 am</td>
<td>St. Andrew’s United Church – 128 – 1st St E</td>
</tr>
</tbody>
</table>

**NANTON**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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<tbody>
<tr>
<td>4th Thursday of the month</td>
<td>10:00 am – 11:30 am</td>
<td>St. Cecilia’s Catholic Church – 2308 – 19th St</td>
</tr>
</tbody>
</table>

### EDMONTON REGION

**CAMROSE**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>2nd Wednesday (will run in Aug)</td>
<td>3:30 pm – 5:30 pm</td>
<td>St. Andrews Anglican Church – 4713 – 50 St NW</td>
</tr>
</tbody>
</table>

**EDMONTON**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>1st Wednesday of the month - South (will run Jul &amp; Aug)</td>
<td>1:00 pm – 3:00 pm</td>
<td>Rutherford Heights – 949 Rutherford Rd</td>
</tr>
<tr>
<td>1st Thursday of the month - Care Partners</td>
<td>10:00 am – 12:00 pm</td>
<td>PA Edmonton Office – 11209 – 86 St NW</td>
</tr>
<tr>
<td>3rd Wednesday of the month - Central (will run Jul &amp; Aug)</td>
<td>7:00 pm – 9:00 pm</td>
<td>PA Edmonton Office – 11209 – 86 St NW</td>
</tr>
<tr>
<td>3rd Friday of the month - North (will run Jul &amp; Aug)</td>
<td>10:00 am – 12:00 pm</td>
<td>Shepherd’s Care – 12603 – 135 Ave</td>
</tr>
<tr>
<td>Jun 28 - Young Onset (Under 50)</td>
<td>6:30 pm – 8:30 pm</td>
<td>PA Edmonton Office – 11209 – 86 St NW</td>
</tr>
<tr>
<td>Jun 8 - Parkinson Plus (PSP, MSA, CBD, etc)</td>
<td>10:00 am – 11:00 am</td>
<td>PA Edmonton Office – 11209 – 86 St NW</td>
</tr>
</tbody>
</table>

**FORT SASKATCHEWAN**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>4th Tuesday of the month</td>
<td>1:00 pm – 3:00 pm</td>
<td>Pioneer House – 10102 - 100 Ave</td>
</tr>
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**LEDUC**

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<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
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<tbody>
<tr>
<td>4th Tuesday (will run Jul &amp; Aug)</td>
<td>6:30 pm - 8:30 pm</td>
<td>Telford House – 4907 - 46 St</td>
</tr>
</tbody>
</table>

**PARKLAND (SPRUCE GROVE/STONY PLAIN)**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>4th Thursday (will run in Aug)</td>
<td>6:30 pm – 8:30 pm</td>
<td>Rehoboth – 3920 49 Ave, Stony Plain</td>
</tr>
<tr>
<td>Location</td>
<td>Date and Time</td>
<td>Venue</td>
</tr>
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</tr>
<tr>
<td><strong>SHERWOOD PARK</strong></td>
<td>2\textsuperscript{nd} Tuesday (will run in Aug) 1:00 pm – 3:00 pm</td>
<td>Bethel Lutheran Church – 298 Bethel Dr</td>
</tr>
<tr>
<td><strong>ST. ALBERT</strong></td>
<td>3\textsuperscript{rd} Tuesday of the month 10:00 am – 12:00 pm</td>
<td>St. Albert 55+ Club – 7 Tache St</td>
</tr>
<tr>
<td><strong>WESTLOCK</strong></td>
<td>Last Monday of the month 1:30 pm – 3:30 pm</td>
<td>Room 140, Provincial Bldg – 2, 10003 – 100th St</td>
</tr>
<tr>
<td><strong>GRANDE PRAIRIE REGION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>GRANDE PRAIRIE</strong></td>
<td>2\textsuperscript{nd} Tuesday of the month 2:00 pm – 4:00 pm</td>
<td>Wildrose Manor – 9358 – 70th Ave</td>
</tr>
<tr>
<td><strong>LETHBRIDGE REGION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>LETHBRIDGE</strong></td>
<td>3\textsuperscript{rd} Thursday of the month 2:00 pm – 3:00 pm</td>
<td>Lethbridge Senior Citizens Org. – 500 – 11th St S</td>
</tr>
<tr>
<td><strong>RAYMOND</strong></td>
<td>Sep 19</td>
<td>Prairie Ridge Centre – 328 Broadway S</td>
</tr>
<tr>
<td><strong>TABER</strong></td>
<td>2\textsuperscript{nd} Tuesday of the month 10:00 am – 12:00 pm</td>
<td>Taber Public Library – 5415 – 50 Ave</td>
</tr>
<tr>
<td><strong>LLOYDMINSTER REGION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BONNYVILLE</strong></td>
<td>Aug 1 &amp; Nov 7 10:30 am – 12:30 pm</td>
<td>Neighborhood Inn (Boardroom) – 5011 – 66 St</td>
</tr>
<tr>
<td><strong>LLOYDMINSTER</strong></td>
<td>4\textsuperscript{th} Tuesday of the month 2:00 pm – 4:00 pm</td>
<td>Southridge Community Church – 5701 – 41 Street</td>
</tr>
<tr>
<td><strong>WAINWRIGHT</strong></td>
<td>1\textsuperscript{st} Wednesday of the month – Care Partners 7:00 pm – 9:00 pm</td>
<td>Provincial Building – 810 – 14th Ave</td>
</tr>
<tr>
<td>**2\textsuperscript{nd} Tuesday of the month 2:00 pm – 4:00 pm</td>
<td>Provincial Building – 810 – 14th Ave</td>
<td></td>
</tr>
<tr>
<td><strong>MEDICINE HAT REGION</strong></td>
<td>2\textsuperscript{nd} Tuesday of the month 1:30 pm – 3:30 pm</td>
<td>PA Medicine Hat Office – 101, 928 Allowance Ave</td>
</tr>
<tr>
<td><strong>MEDICINE HAT</strong></td>
<td>2\textsuperscript{nd} Wednesday of the month 1:30 pm – 3:00 pm</td>
<td>PA Medicine Hat Office – 101, 928 Allowance Ave</td>
</tr>
<tr>
<td>**4\textsuperscript{th} Tuesday of the month 1:30 pm – 3:30 pm</td>
<td>Crossroads Church – 1340 – 22 St SE</td>
<td></td>
</tr>
<tr>
<td>**4\textsuperscript{th} Wednesday of the month – Women with PD 1:30 pm – 3:00 pm</td>
<td>PA Medicine Hat Office – 101, 928 Allowance Ave</td>
<td></td>
</tr>
<tr>
<td><strong>RED DEER REGION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CASTOR</strong></td>
<td>Jun 26 1:30 pm – 3:30 pm</td>
<td>Paintearth Lodge – 4501 – 55 Ave</td>
</tr>
<tr>
<td><strong>INNISFAIL</strong></td>
<td>1\textsuperscript{st} Wednesday of the month 10:30 am – 12:30 pm</td>
<td>Church of the Nazarene – 4904 – 48 St</td>
</tr>
<tr>
<td><strong>LACOMBE</strong></td>
<td>4\textsuperscript{th} Wednesday of the month 10:00 am – 12:00 pm</td>
<td>Wolf Creek Community Church – 4110 Hwy 12</td>
</tr>
<tr>
<td><strong>OLDS</strong></td>
<td>2\textsuperscript{nd} Wednesday of the month 1:30 pm – 3:30 pm</td>
<td>Sunrise Village – 5600 Sunrise Cres</td>
</tr>
<tr>
<td><strong>RED DEER</strong></td>
<td>3\textsuperscript{rd} Wednesday of the month 10:30 am – 12:30 pm</td>
<td>Davenport Church of Christ – 68 Donlevy St</td>
</tr>
<tr>
<td><strong>THREE HILLS</strong></td>
<td>Jun 6 2:00 pm – 4:00 pm</td>
<td>Community Drop In Centre</td>
</tr>
</tbody>
</table>
Reflections of a Research Student

By: Vineet Prasad, MSc Rehabilitation Science Student

What do we know?

Primarily two groups of symptoms “motor” and “non-motor” characterize Parkinson disease. The cardinal motor features include the symptoms such as rigidity, bradykinesia, postural instability, and tremors. Usually, motor symptoms start on one side of the body with the contralateral involvement appearing within a few years. Disturbances in autonomic function, sleep disturbances, cognitive and psychiatric disturbances and sensory symptoms are common non-motor symptoms. Some of the non-motor symptoms such as sleep disorders manifest before the onset of motor symptoms.

Sleep disorders such as excessive daytime sleepiness (EDS) may start as early as ten years before the beginning of motor symptoms and about 15 to 74% People with Parkinson disease (PWP) experience excessive daytime sleepiness. There are diverse reasons which might lead to daytime sleepiness including dopaminergic medications, unhealthy sleep schedules, depression. Excessive daytime sleepiness can cause cognitive impairment that can range from mild to severe, with deficits in attention, memory, and judgment.

Moreover, persistent EDS contributes to social problems such as decreased social engagement and automobile accidents. Besides safety concern in PWP who continue to drive, there is also the potential for loss of independence, increased caregiver burden, and further impairment of quality of life for those who are unable to drive due to EDS. Therefore, there is a need for early recognition and management of EDS not only to increase health-related quality of life but also to ensure patient safety.

So how can we manage it?

Currently, the options available for management of daytime sleepiness are very few. These includes consulting your physician and if required tapering the dose after consulting your doctor. Medicine such as modafinil is prescribed, but recent studies show that there is insufficient evidence to support or refute a safety benefit for modafinil in PWPD with EDS. Apart from drugs, non-pharmacological treatment such as relaxation therapy, stimulus control has shown to provide slight relief to the people experiencing daytime sleepiness. However, these treatment options provide psychological effect rather than direct physiological effect. Also, these treatments are not effective for someone who is having some cognitive impairment.

What am I doing?

My research focuses on reducing the daytime fatigues by altering the disrupted circadian rhythm seen in people with Parkinson disease experiencing daytime sleepiness.

Studies have shown that PWPD experiencing daytime sleepiness have disrupted circadian rhythm. The circadian rhythm is affected by exposure to bright light, and hence bright light has been successfully used in management of other sleep disorders such as insomnia, various form of depression and psychiatric disorder. However, for PWPD experiencing EDS no such evidence to refute or accept BLT as an intervention.

I will be testing the outcome of BLT exposure to reduce EDS in PWP and I hope that this will help restore disease-disrupted circadian rhythm, thus
contributing to a healthy sleep–wake cycle and decreased perceived daytime fatigue.

Why am I doing it?

Before coming to Canada, I was working as a physical therapist in India. Also, I am working with a non-profit organization which works for the benefit of PWPD. The majority of the people coming to group told me about their experience concerning daytime sleepiness. I was quite moved about the fact that even though sometimes they do not wish to sleep, but they doze off. Also, one more thing which drew my attention was the fact that daytime sleepiness was consuming their productive time and in few cases people had shunted themselves away from the society. So, I decided to do something about the daytime sleepiness, and I came over here in Canada to work on a solution for PWPD experiencing EDS.

References

CHICKEN WING CHALLENGE

COMPETE IN A HEAD TO HEAD BATTLE TO DETERMINE WING EATING SUPREMACY

EDMONTON
June 20
Hudsons Canada’s Pub
2104 - 99 St

LETHBRIDGE
June 21
Hudsons Canada’s Pub
904 2nd Avenue South

Call or visit our website for details or to register

www.parkinsonalberta.ca/chickenwingchallenge

Parkinson Alberta
2ND ANNUAL
Malts ‘n Barley
WHISKEY & BEER TASTING FESTIVAL

June 23, 2017 | Pomeroy Hotel & Conference Centre, Grand Prairie
6:30pm-10:30pm | Tickets: $75/person

Call or visit our website for details or to purchase your tickets today!

97.7 ROCK

SAVE THE DATE
July 6, 2017
Sirocco Golf Club, Calgary

Online Registration is open!
2017 Hope Conference
Your Tools for Living Well with Parkinson’s

Saturday, May 27

Calgary
Thorncliffe Greenview Community Association

Edmonton
Central Lion’s Recreation Centre

Grande Prairie
Elk’s Hall

Lethbridge
Lethbridge Senior Citizen Organization

Lloydminster
Southridge Community Church

Medicine Hat
Holiday Inn Express

Red Deer
Davenport Church of Christ

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