

Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



LEARNING INTO LIFE

Coping with **Loss & Grief**



Holiday Celebrations



**FORT
SASKATCHEWAN**

November 26
Holiday Potluck

CALGARY

December 6
Holiday Potluck

SHERWOOD PARK

December 10
Holiday Potluck

WAINWRIGHT

December 10
Boston Pizza
Lunch

GRANDE PRAIRIE

December 11
Holiday Potluck

MEDICINE HAT

December 11
Medicine Hat
Buffet Lunch

OLDS

December 11
Holiday Potluck

COCHRANE

December 12
Holiday Potluck

LLOYDMINSTER

December 14
Turkey Dinner

CASTOR

December 17
Holiday Potluck

LEDUC

December 17
Holiday Potluck

RED DEER

December 18
Holiday Potluck

LETHBRIDGE

December 19
Holiday Potluck

BONNYVILLE

December 20
Neighbour Inn
Lunch

EDMONTON

December 20
Holiday Potluck



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9,14 Saturday
February 29, 2020

FALL 2019

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

Parkinson Association of Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.

Parkinson Association of Alberta Head/Calgary Office

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

Parkinson Association of Alberta Edmonton Office

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

Parkinson Association of Alberta Grande Prairie Office

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

Parkinson Association of Alberta Lethbridge Region

PO Box 333
Lethbridge, AB T1J 3Y7
T 403-317-7710

Parkinson Association of Alberta Lloydminster Region

PO Box 122
Lloydminster, AB T9V 3A2
T 780-808-5006

Parkinson Association of Alberta Medicine Hat Region

PO Box 23063
Medicine Hat, AB T1B 4C7
T 403-526-5521

Parkinson Association of Alberta Red Deer Region

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

Parkinson Pulse is available (both past and present issues) as a free download via our website. Hard copies are available for mail out to current Members who wish to receive one.

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

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From the Desk of **THE CEO**



Loss is a human experience. People across the globe experience a wide range of losses — deaths, breakups, loss of physical or mental health and other changes or transitions. In fact, a quick internet search shows there are at least a dozen different types of loss and grief. It is important to note however that grief and loss are two very distinct things.

Loss is the event that takes place, grief is the reaction to the loss. What is common is that the losses and ensuing grief can leave you feeling like you're lost in a maze of what was, what is and what could be.

When it comes to a progressive chronic disease like Parkinson disease, the losses can sometimes feel like they just don't stop ([page 07](#)). And, because the losses (loss of physical ability, loss of independence, loss of future plans to name a few) don't fit society's traditional understanding of loss, the individuals and families experiencing these losses may end up feeling isolated and alone.

In this issue we tackle the often difficult and complicated topic of loss and grief ([page 06](#)). We take a look at the complexities of ambiguous loss ([page 08](#)) where there is a loss (with no death) that can leave you struggling to understand, breathe or even function as you try to pick up the pieces.

A deep and significant loss isn't something you "move on" from or "get over." It is life-changing; forever altering the fabric of your being. And the grief that follows is rarely

singular, coming rather in waves or cycles – often when you least expect it. A memory of dancing in the rain. The way they used to smile or laugh. During holidays or major life events. Even watching a stranger do something you can no longer do. In order to "break on through to the other side" as the Doors so succinctly put it, you have to learn to move through the losses and grief ([page 10](#)).

To varying degrees, research also takes a look at the losses attributed to Parkinson disease. From physical ability to cognitive impairment, dementia to the impact on spouses (and more) – research delves into different aspects aiming to find ways to create a brighter future for those impacted by Parkinson's. Parkinson Association of Alberta is happy to support and promote research trials taking place right here in Alberta ([page 12](#)).

To ensure no one has to face their Parkinson journey alone, Parkinson Association of Alberta offers a number of no and low cost support services and program options. To help alleviate the cost of these offerings we rely on donations and memberships ([page 15/16](#)) and host exciting events like our annual Parkinson Step 'n Stride and our brand new "Main Event" being held this February. I encourage you to find out more about the support and services we offer and how YOU can get involved!

John Petryshen

CEO, Parkinson Association of Alberta

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A Miracle!

Written by: J. H. Sprague, MD, FRCPC

In the early 1950's when I was in high school, I began to notice some changes in my father.

Dad was a physician and in those days, doctors took phone calls from patients, their families and they even made house calls on a regular basis. Needless to say, the telephone desk in our sunroom was frequently in use with Dad's professional calls. Despite being an MD, his writing had always been very neat and very legible. I noticed however that the notes he would take at the desk revealed that his writing was changing. The letters were small and the structure of the letters, rather than being concise, were somewhat irregular. As time went on, we noticed that his voice was becoming weak and we were constantly asking him to speak up. He was also slowing down and simple things like eating and dressing were taking an inordinate amount of time. It was during this time that Dad consulted a local neurologist at the University Hospital in Edmonton and the diagnosis of Parkinson disease was made. He was placed on the usual Parkinsonian drugs in use at that time, but they were of no significant benefit. His condition continued to deteriorate and he was forced to terminate his medical practice.

In the late 60's I began to read about the use of L-dopa in Parkinson disease. I had written to the pharmaceutical companies initiating trials, but I had not heard back from any of them. A short time after that, my father wanted to attend a Regional Meeting of the American College of Physicians being held in Banff. For years Dad had been Governor representing Alberta for the American College and he wished to meet up with some of his old friends once again. It was during



this meeting, I ran into the travelling secretary for the American College who happened to know Dad very well. I asked him if he was aware of any trials of L-dopa being done in the USA. He was not, but offered to research this once he returned home. Two weeks later he phoned me with news that there was a trial being done at the Mayo Clinic in Rochester, Minnesota and that the neurologist involved in the trial was Dr. Manford Muentert.

My dad had done his fellowship at the Mayo Clinic back in the early thirties and I had followed his footsteps in the mid-sixties. While I was doing my residency training in neurology the senior resident was Manford Muentert. I contacted Manford directly and told him of Dad's problem. He very kindly offered to accept Dad into his drug trial and wondered how soon he would be able to come. I put Dad on the plane that evening and he arrived in Rochester the next day. By this time Dad was so disabled, he was put on the plane by wheelchair.

Dad was at the Mayo Clinic for several weeks and we were receiving reports from Mother that he was progressing very well. He was discharged home on L-dopa and on arrival walked off the plane unassisted and moved about much like his old self. He was later switched to Sinemet (L-dopa + Carbidopa) which made the administration of the L-dopa far easier and with fewer side effects. This drug fortunately gave my father many more years of life which he otherwise would have missed.

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NEWS + updates



• WE'RE COMING TO A COMMUNITY NEAR YOU!

Education is a key focus at Parkinson Association of Alberta which is why we schedule and welcome opportunities to present to community members, organizations, post-secondary institutions and others. Our presentations aim to educate attendees on Parkinson disease as well as the supports and services available.

Over the past few months our staff have done presentations in the following communities: Blairmore, Calgary, Crowsnest Pass, Edmonton, Edson, Fort MacLeod, Linden, Picture Butte, Pincher Creek, Raymond, Taber, Torrington, Trochu and Whitecourt.

If you are interested in hosting a presentation, please contact the Office closest to you (page 2) or call us tollfree at **1-800-561-1911**.

- **DUODOPA SUPPORT GROUP** Parkinson Association of Alberta is considering starting a support group in the new year specifically for people who have undergone the Duodopa procedure and their Care Partners/families. If you would be interested in participating this type of group please call tollfree **1-800-561-1911** or email **communications@parkinsonassociation.ca**

• PAA CLIENT SERVICES AND QUALITY OF LIFE SURVEYS

We'd like to extend a big THANK YOU to everyone who completed the Client Services Survey that circulated earlier this fall. Your input and feedback will assist the Client Services Team as they begin planning the direction, services and offerings for 2020!

We are also currently circulating our annual Quality of Life (QoL) Survey (for both people with PD and their Care Partners/Family Members). By completing this survey, you help Parkinson Association of Alberta by providing real, honest and valuable insight on Parkinson disease and its effects on day-to-day living. This information not only helps our Client Services Coordinators to provide support and services tailored to meet YOUR individual needs; but also is compiled into a bigger picture so that we can advocate to the government and Alberta Health for a brighter future. If you have not received your QoL survey, please let us know!



• OFFICE CLOSURES

- All PAA Offices will be closed on **December 2 and 3** to accommodate in-person staff meetings. We will return to regular operating hours on Wednesday, December 4.
- All PAA Offices will be closed for Winter Break from **Monday, December 23 through Wednesday, January 1**. We will return to regular operating hours on Thursday, January 2, 2020.

Coping with Loss & Grief



Written by: Brandi La Bonte

Loss is an inevitable part of life. And, if loss is an inevitable part of life, then so too is grief which is a natural part of the healing process. More often than not, people associate loss primarily with a death. And while, of course death is a significant loss; loss is not exclusively about the physical death of a person.

We are born, we live and, ultimately, we do die. Death is painful and sad, however, for the most part people know what to do. There are condolences, rituals, ceremonies and even a section in amongst the greeting cards. But what about loss that isn't experienced due to death? Does it count as a loss? Can it be considered traumatic? Is it ok to grieve? Does one need to heal from it?

Feelings of loss are very personal and there are many examples that are both common and maybe a little less obvious. These can include, but are not limited to:

- **Death of a loved one or someone close to you**
for example a spouse, family member, friend or even a pet
- **Serious illness and/or loss of health**
for yourself, a loved one or someone close to you
- **Ending of a significant relationship**
be it romantic, familial or friendship
- **Abuse and/or trauma**
- **Leaving home**
this can include having a child move out, downsizing or transitioning into long term care
- **Change or loss of physical ability**
this could include a temporary or permanent change/loss due to accident, illness, infertility or even simply the aging process
- **Change or loss of a job and/or financial security**
- **Change or loss of future plans, anticipated outcomes or goals**

things a human can face; other types of losses can also bring about similar feelings. These can include feelings of being overwhelmed, incapacitated, empty, hopeless and/or helpless. What makes this even more complicated is that often times others (in our circle or peripherally) do not apply the same empathy or support to non-death losses as they would to the death of a loved one. Well-meaning people encourage those experiencing non-death losses to "shake it off", "move on" or "let it go."

Accepting loss is extremely challenging. And, grief doesn't fit neatly in a box. Regardless of the type of loss one is experiencing, it is important to recognize that the grief is real. Some forms of grief take years to work through, other types take a few solid months, while some take but a single moment of deep acknowledgement.

Grief is the normal process of reacting to a loss. Grief may be experienced as a mental/emotional, physical or social reaction; or a combination thereof.

- Mental/emotional reactions can include feeling anger, guilt, anxiety, disbelief, sadness, emptiness, loneliness and/or despair.
- Physical reactions can include sleeping problems, changes in appetite, physical problems (headaches, aches, pains) or illness.
- Social reactions can include feeling pressure to be strong for others, having others avoid the person who is grieving or even isolating one's self.

When one experiences a significant loss (or losses), it can turn one's life completely upside down and play havoc with mental/emotional, physical and social health. Remember that everyone reacts to loss differently, so one shouldn't get caught up with worrying about whether grief is being managed in the 'right' way. It is important to allow the grieving person to feel how **they** feel, and grieve properly so that they can eventually start to feel better.

So while death is probably one of the most challenging

Loss, Grief and Parkinson Disease

Written by: Brandi La Bonte



In 1969 Elizabeth Kübler-Ross introduced the world to the five stages of grief (denial, anger, bargaining, depression and acceptance). While that is fairly well-known, what isn't is that *"Kubler-Ross didn't originally develop these stages to explain what people go through when they lose a loved one. Instead, she developed them to describe the process patients go through as they come to terms with their terminal illnesses."*¹ But what happens when one's illness isn't terminal but progressive and chronic in nature taking place over a period of years...even decades?

When individuals and families first learn they or their loved one has a progressive chronic illness, like Parkinson disease, it is normal and natural for them to associate the diagnosis with a loss and experience grief. Beyond the initial diagnosis, losses due to Parkinson disease (directly and indirectly) involve an ongoing decline of functioning ability. These declines may include ongoing physical, cognitive and emotional changes that may adversely affect not only overall health and wellness, but day-to-day life. Other losses may include future or anticipated goals/plans, independence, ability to work, income and friends or family to name a few. Combined, these **infinite losses** are likely to drain individuals and families physically and emotionally because they occur over a long period of time, often many years. And, because the losses are ongoing, multiple, and in most cases permanent they may be difficult to resolve and may end up piling up without dealing with the necessary grieving process. This then can lead to new losses stirring up emotions related to past losses, while past losses may magnify and complicate one's ability to deal with the ongoing new losses.

It's complicated to be sure. Grief associated with death and even terminal illness, while devastating and sad, has a perception of closure and there is usually a return to "normal" day-to-day life. It is simply not the same for a progressive chronic illness where the losses are not just about a loss of "self", but also loss of opportunities and physical/cognitive ability triggered by changes in the person's condition. Kate Jackson paints a clarifying picture in an article she wrote for Social Work Today:

*"Imagine a person with a chronic illness as forever walking down a dividing line between the past and the future. Looking backward, he can see everything illness has taken from him or has forced him to relinquish. Looking forward, he can't see anything quite clearly. There's no going back to the past, and the future is uncertain."*²

Dealing with loss and grief can be daunting and difficult, but it is beneficial...and there is healing and hope in working one's way through the grieving process. Moving through grief allows individuals and families to discover how to live a more deeply engaged and meaningful life. Benefits can include (but are not limited to):

- **closer relationships with family and friends**
- **an ability to focus on what is there, not what is missing**
- **a better understanding of how to choose to be happy**
- **better overall health (including less stress and better sleep)**
- **establishing a solid support base**
- **better insight into one's self**
- **redefined priorities**
- **a changed perspective on life**
- **building coping skills and resilience**
- **recognizing you are not alone**

**Life is transient and time is fleeting; make it worthwhile...
Lean into Life**

References:

- ¹ Feldman, David B., PhD (July 2017). "Why the Five Stages of Grief are Wrong." Retrieved on October 22, 2019, from www.psychologytoday.com
- ² Jackson, Kate. (2014). "Grieving Chronic Illness and Injury — Infinite Losses." Social Work Today. Retrieved on October 22, 2019, from www.socialworktoday.com.

It's Hard to Say Goodbye – Understanding Ambiguous Loss

Written by: Brandi La Bonte

A loss that happens where there is no death (like a break up, a soldier missing in action, or a diagnosis of dementia or Alzheimer's, etc) is a unique kind of loss. One that more often than not comes without any kind of perceived closure but retains the familiar experience of the pain, sadness, anger, etc of a more "traditional" loss. This type of loss has a name, ambiguous loss.

According to Dr. Pauline Boss, emeritus professor and researcher at the University of Minnesota, who first coined the phrase "ambiguous loss" in the 1970s; there are two types of ambiguous loss:

The first type is a physical absence with a psychological presence; meaning someone who is absent/missing physically but is kept alive psychologically. Examples of this can include losses experienced through divorce, or a significant breakup, migration, adoption, service commitments, disappearance, and catastrophic experiences. In some cases these are accompanied by an underlying hope that the loved one will reappear.

The second type of ambiguous loss is when a loved one is physically present but psychologically absent. Examples of this include the aging process with accompanying loss of cognitive functioning, dementia, physical illnesses, brain injury, coma, addictions, and mental health issues. In this instance a loved one is physically there (we can see them, talk to them, touch



them, etc) but absent psychologically (they are not there emotionally). There is an emotional "death" before the physical one.

Dealing with loss of any kind is difficult and those making their way through a loss –including ambiguous loss -- deserve understanding and support. The ambiguity in these types of losses doesn't make it any less real or hurt less. The ache of stolen future plans and memories are just as real. The graduations, weddings, or other family events missed because of mental illness or addictions. Caring for someone who has dementia or Alzheimer's which robs the person you love of their personality and memories. All these moments have significance in what won't be possible. Hopes, dreams and life plans change. These losses are tangible.

Managing the ambiguity can be like trying to find your way in the fog. You keep moving forward, despite the stress of not knowing what lies ahead. There will be days when you will feel stronger than ever and days that will bring you back to your knees. You keep moving forward and, as with many other of life's challenges, you reach out for support and human connections to stay resilient and strong. In this you may no longer feel so alone knowing that someone is listening to your concerns, that there are others going through a similar experience and that you can learn strategies for living with the losses, allowing yourself to grieve as part of the process of adjusting to loss.

Tasks of Ambiguous Loss (Boss-1999)

- **Find Meaning** - Look at values, beliefs and traditions. Remove blame and guilt.
- **Accept Uncertainty** - Change the way one thinks of the loved one- they are both here and not here. Balance need for control with acceptance of ambiguity, externalize blame.
- **Reconstruct Identity** - Roles and family dynamics change.
- **Learn to live with ambivalence as a new norm** - Conflicting feelings, accept emotional rollercoaster, develop coping strategies.
- **Revisit Attachment** - Celebrate the missing and mourn the changes.
- **Discover Hope** - Look at strengths, discover hope in different ways.

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Life After Loss – Dealing with Grief

Written by: Brandi La Bonte

The loss of someone or something significant in our lives often causes a psychological pain that simply cannot be avoided, no matter how hard we try. In fact, the harder we try to distract ourselves from, avoid dealing with or suppress our feelings about the loss the more of a problem it becomes. Our efforts to “carry on” are exhausting, ultimately fail and the painful reality of the loss returns.

The emotions we experience after a significant loss will vary and change – not just over time, but from person to person as well. The way we deal with loss and move through the grieving process depends on a lot of things: the type of loss we’ve experienced, our personality, our upbringing and/or cultural background, our relationships, our physical and mental health, and even our age.

When a significant loss takes place, we may experience a wide range of emotions, even when the loss was expected. Many individuals report feeling an initial stage of numbness after first experiencing the loss, but ultimately there is no true order to the grieving process.

Grief is not a linear process, but is more often experienced in cycles. Think of it in terms of climbing a spiral staircase – it feels like we are just going in circles, when we are in fact moving forward.

Some of the feelings we may experience are:

- **Denial**
- **Confusion**
- **Disbelief**
- **Shock**
- **Anger**
- **Yearning**
- **Despair**
- **Sadness**
- **Betrayed**
- **Humiliation**
- **Guilt**
- **Relief**



So what are some things we can do to work through our own grief process?

Give it time

It can take a really long time to work through our lowest moments when we have suffered a significant loss, and it’s normal to feel like life has been turned upside down for a while. It won’t always be this hard. Time will eventually help heal the emotional pain.

Cover the basics

Keep a day-to-day routine up (make the bed, take the kids to school, walk the dog, etc), get plenty of rest and eat healthily. Avoid things that temporarily “numb” the pain like alcohol and non-prescribed narcotics.

Keep a journal

Writing down our feelings about a loss, as well as memories is a great way to track how grief is changing as the weeks and months pass. It can help reassure us during difficult patches that we’re making progress.

Participate in or create a ritual or ceremony

Grief rituals and ceremonies acknowledge the pain of loss while also offering social support and a reaffirmation of life. Talking with family, friends or clergy is one way to strengthen our awareness of possible cultural influences in our lives. And, friends and family can help us generate ideas to create our own rituals.

Talk to someone

Grieving can feel very lonely and be a long process; talking is often a good way to soothe painful emotions. Finding someone to talk to, such as a friend or family member, elder, religious leader, health professional or counsellor can help to begin the healing process. Support groups can also be beneficial as a lot of people find it helpful to talk to people who have been through similar experiences.

If any or all of the above strategies have been undertaken, and one is still finding it difficult to deal with the loss and/or losses it is a good idea to seek professional help (such as a general practitioner, psychiatrist or psychologist).

Professional help should also be sought if any of the following apply:

- Experiencing symptoms of depression/anxiety
- Feeling unable to cope with overwhelming emotions or daily life
- The intense emotions are not diminishing or are getting worse as time passes
- Persistent insomnia
- Relationship is suffering (anger, isolation, sexual issues)

Working through a loss and the subsequent grieving process may be easier and potentially faster if one has professional support. Healthy coping skills are important in resolving a loss and helping you move forward in the healing process.



An Oath to One's Self When Grieving a Loss...

1. **I acknowledge I have the right to grieve this loss. My feelings towards the person(s) or thing(s) I've lost are real, significant, and no less important than anyone else's.**
2. **I acknowledge that my grief and I deserve the time and space needed to process and deal with the loss. I will not let others minimize this need or deprive me of my right to grieve.**
3. **I understand that there are others who are grieving similar losses. I will be open to the possibility of receiving support from those who have had similar experiences.**
4. **I acknowledge that I have the right to rituals honoring and remembering my deceased loved ones and other losses.**
5. **I choose to be supported by those who validate my loss and support me in my grief. I choose not to engage with those who belittle me and treat my feelings as invalid.**
6. **My loss is real and I must find personal ways to explore and express my grief and emotion.**
7. **I'll take what I've learned from my own grief and loss and strive to show sensitivity towards the grief and loss experience of others.**

Participate in Research

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

Parkinson Association of Alberta's mission is to make every day better for Albertans impacted by Parkinson disease and Parkinson's Plus Syndromes. We do this not only by offering "right now" opportunities (such as one-on-one/family supportive counselling, support groups, education and programs); but also by keeping an eye on the future through funding and promotion of research.

Researchers around the world, including right here in Alberta, are working to identify and address various issues associated with Parkinson's. Alberta is home to many talented researchers who are taking on Parkinson disease from a variety of perspectives, all aimed at having a positive impact in the lives of people affected by Parkinson's. Over the past five years Parkinson Association of Alberta has contributed over **one million** dollars to Parkinson's research right here in Alberta.

The fight to create a brighter future for those impacted by Parkinson's; and ultimately end Parkinson disease is both challenging and multifaceted. Two of the biggest challenges associated with research are funding and participation, or rather a lack of both. The good news is that both of these challenges can be addressed at an on-the-ground level. Making a charitable donation and/or participating in research trials are two of the best ways YOU can contribute to the fight.

Research trials are a key component of research and are at the core of all medical advances. If you feel participating in a research study is something you are interested in, we encourage you to view the available opportunities to find out if there is a good match available for you. Please note that interested individuals are not necessarily guaranteed acceptance into a study. The information listed below is limited to generalities; to find out more about the research participation opportunities listed below, please visit our website at <http://parkinsonassociation.ca/champions-of-hope-participate>

• Quality of Life with Multiple System Atrophy (MSA) Study

Who is eligible	People with MSA and/or Care Partner/Spouse
Type of Participation	A one hour interview (telephone or in person at the Kaye Edmonton Clinic) and completing questionnaires

• Does Living with Parkinson Disease Impact Life-Space Mobility? A Mixed Methods Study

Who is eligible	People with Parkinson's
Type of Participation	A 20 minute interview (telephone or in person at the University of Alberta) and completing a questionnaire

• Impact of Parkinson's Patients Delusions on their Spouses Study

Who is eligible	Care Partner/Spouse of a Person with Parkinson's who has/had Parkinson's-related delusions
Type of Participation	A one hour interview/study visit conducted in person at the Kaye Edmonton Clinic



- **Getting Older Adults Outdoors Study**

Who is eligible	People with and without Parkinson's; aged 65 or older
Type of Participation	Attend 2hr interactive workshop and 4 in-person sessions at the Bone and Joint Clinic (Edmonton)

- **Parkinson's Daytime Sleepiness Study**

Who is eligible	People with Parkinson's
Type of Participation	Use of supplied light box for 30 minutes each day for 3 weeks

- **Comprehensive Assessment of Neurodegeneration and Dementia Study**

Who is eligible	People with Parkinson's
Type of Participation	Five onsite visits over 12 weeks at the University of Alberta

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

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

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

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

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

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

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

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



To find out more about Parkinson Association of Alberta's commitment to research, visit our website

parkinsonassociation.ca/champions-of-hope-home

EVENTS + updates

UPCOMING EVENTS

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

Parkinson's Perk Coffee Campaign

The holiday season will be here before you know it - Fill your stockings with a tasty bag of Parkinson's Perk! 1lb bags are \$10 each and available in your region, please contact your regional office or call tollfree **1-800-561-1911**.

The Main Event

Saturday, February 29, 2020 – JW Marriott – Edmonton

KNOCK OUT Parkinson Disease at the **MAIN EVENT** this February!

Presented by Parkinson Association of Alberta & Bayshore Home Health this gala evening will take place **Saturday, February 29th, 2020** at the prestigious JW Marriott Edmonton ICE District.

The event will include special guest **Jelena Mrdjenovich**, current WBC Featherweight Champion of the World and WBA World Champion, FOUR fights, world class cuisine, music, and more!

For more information or to get your tickets today visit parkinsonassociation.ca or call **1-800-561-1911**.



PAST EVENTS

Tap'd Out Food + Beverage Festival – Red Deer

On Monday, August 12 twelve breweries, one secret ingredient and one amazing cause came together for a friendly competition. Guests were able to taste these unique brews and judge who they thought brewed it best! The event took place at Bo's Bar and Grill where over 150 guests joined us and raised over **\$5,000!**



15th Annual Mark Mercier Golf Tournament - Edmonton

On Monday, September 9, 2019 the Mark Mercier Foundation partnered with PAA for an amazing day at the beautiful Windermere Golf and Country Club. We had fabulous food and beverage vendors, a silent auction and raffle!

A huge Thank You to our sponsors and hole activities: Black Cat Wear Parts, Universe Machine, B Wright Drywall, NorthWind Land resources, Imperial Equities, ROAR Organic, Steamwhistle, Rig Hand Distillery, Service Master, Boston Pizza, Blackfly Beverages, Edmonton International Airport, 5 Star Promotional Advertising, Signarama, Martin Motor Sports, Proximo Spirits and more! Total funds raised was **over \$40,000!**

28th Annual Parkinson Tulip Golf Tournament - Calgary

Due to a rainout in July we moved our Calgary Golf Tournament to Monday, September 16! The day was warmer with no rain and lots of smiles at Silver Springs Golf and Country Club. Total funds raised was **over \$60,000!**



October 2019

Dear Friend,

On behalf of Parkinson Association of Alberta's members, clients and care partners, we sincerely thank you for your support of programs, services and Research in Alberta.

My wife Judy, was diagnosed with Parkinson disease (PD) four years ago when we noticed a tremor in her left hand. Following the diagnosis, my daughters and I understood the reason why Judy was so exhausted and stiff in the morning. The Calgary Client Services Coordinators, provided us with as much information on PD we could handle, and encouraged us, when we were ready, to participate in the wonderful programs and services offered by the association. Without any hesitation, Judy signed up for the PWR!Moves™ program, and continues to participate in the program to this day. The program is specifically designed for people with PD that stimulates both the mind and body, counteracting its negative effects.

We are honoured to serve as chairs of Parkinson Association's (PAA) 2019 Annual Gift Campaign.

Together we attend many education sessions on various topics on PD, we attend monthly support groups and care partner meetings intended for both the person living with PD and their care partners. As well, we have attended several information sessions targeted to Research. Through these activities, we have learned we are not alone in our PD journey. We have met others who also are navigating through their PD challenges and are just as passionate as we are about the cause. Judy and I have learned so much more by listening to their stories, creating a new social network of people who support each other mentally and physically.

On an annual basis, we fund raise and participate in the Flexxaire Parkinson Step 'n Stride Walk. Our team "The Striders" raise much needed funds for Parkinson Association of Alberta to continue to provide the support and services needed for people living with or affected by

Parkinson disease. We are pleased to say, our team raised over \$40,000 this year.

We hope this letter will explain why we are so passionate about PAA. We are writing this letter to ask you to consider making a donation to the best of your ability, as well as to become a member or renew your membership with Parkinson Association of Alberta. Your donation will ensure that during these difficult times, PAA can continue helping people live well with PD while also supporting important ongoing Research. We aim to provide the best possible quality of life services for those who are affected by Parkinson disease. As a not-for-profit, charitable organization, our funding is primarily sourced from memberships, donations, memorials, bequests, and event fundraising. We do not receive core government funding for our services, nor do we solicit funds through door-to-door canvassing or telemarketing campaigns.

Please consider making a gift to Parkinson Association of Alberta. With your help we can ease the burden in the lives of people with Parkinson disease, expand our programs and services, and search for a cure.

Sincerely,

A handwritten signature in black ink, appearing to read "Ron & Judy Bing".

Ron & Judy Bing
2019 Annual Gift
Campaign Chairs

A handwritten signature in black ink, appearing to read "John Petryshen".

John Petryshen
CEO, Parkinson
Association of Alberta

Please see next page for the Annual Gift Campaign Form or call us tollfree at 1-800-561-1911



I would like to:

- ☐ Become a Member (\$25)
☐ Renew my Membership (\$25)

I would like to make a tax deductible contribution in the amount of:

☐ \$35 ☐ \$75 ☐ \$125

☐ Other \$ _____

I would like my donation to support:

- ☐ Support & Services ☐ Research

Please send my membership card and/or tax receipt to:

Name: _____

Address: _____

City, Prov. & PC: _____

Telephone Number: _____

- ☐ I would like to receive email communications from Parkinson Association (including updates and information)
☐ Enclosed is my cheque made payable to: **Parkinson Association of Alberta – 120, 6835 Railway St. Calgary, AB T2H 2V6**
☐ Please charge my VISA, Mastercard, or American Express

A Monthly Donation option is also available

Please charge my VISA, Mastercard, or American Express monthly for _____ months

Name as it appears on the card: _____

Card Number: _____ / _____ / _____ / _____

Expiry: _____ / _____ Card Security Number: *(Back of the card)* _____

Signature: _____ Total Amount: \$ _____

If you prefer, donations may be made online at
www.parkinsonassociation.ca or call toll-free 1-800-561-1911.

- ☐ Please contact me about Planned Giving Opportunities

Parkinson Association of Alberta respects your privacy. The information you provide will be used to keep you informed on the activities of the organization. If you wish to be removed from these contacts, or would like more information about donor privacy, please call 1-800-561-1911.

SUPPORT GROUPS

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

ALBERTA		1-800-561-1911
ARTA CHARITABLE FOUNDATION'S TELE-SUPPORT GROUPS		
3 rd Wednesday - Care Partners	6:30 pm – 7:30 pm	Advance registration is required to receive call-in instructions & a passcode; call the above number.
3 rd Thursday - General Parkinson's	10:00am – 11:00am	
4 th Thursday - Parkinson's Plus Syndromes	10:00am – 11:00am	
CALGARY REGION		403-243-9901
AIRDRIE		
3 rd Tuesday	10:00 am – 11:30 am	Cam Clark Ford – 1001 Highland Park Blvd
CALGARY		
1 st Tuesday – Northwest	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
1 st Thursday – Northeast	10:00 am – 11:30 am	Ascension Lutheran Church – 1432 - 19 St NE
2 nd Tuesday – Southeast	10:00 am – 11:30 am	PAA Calgary Office – 120, 6835 Railway St SE
3 rd Tuesday - Care Partners	1:30 pm – 3:00 pm	PAA Calgary Office – 120, 6835 Railway St SE
3 rd Thursday - Southwest	10:00 am – 11:30 am	Riverpark Church – 3818 - 14A St SW
3 rd Saturday - Parkinson's Plus Syndromes	12:00 pm – 2:00 pm	Bass Pro Shop Mtg Rm – 261055 Crossiron Blvd
4 th Tuesday - Southeast	10:00 am – 11:30 am	PAA Calgary Office – 120, 6835 Railway St SE
4 th Tuesday - Young Onset	7:00 pm – 9:00 pm	Hope Lutheran Church – 3527 Boulton Rd NW
CANMORE		
2 nd Thursday	1:30 pm – 3:00 pm	920 Fairholme Dr
COCHRANE		
2 nd Thursday	10:00 am – 11:30 am	St. Andrew's United Church – 128 – 1 st St SE
NANTON		
4 th Thursday	10:00 am – 11:30 am	St. Cecilia's Catholic Church – 2308 – 19 th St
STRATHMORE		
1 st Thursday	1:30 pm – 3:00 pm	Hope Community Church – 245 Brent Blvd
EDMONTON REGION		780-425-6400
CAMROSE		
2 nd Wednesday	3:30 pm – 5:30 pm	Bethel Lutheran Church – 4102 – 73 St
EDMONTON		
1 st Wednesday - South	1:00 pm – 3:00 pm	Rutherford Heights – 949 Rutherford Rd
1 st Thursday - Care Partners	10:00 am – 12:00 pm	PAA Edmonton Office – 11209 – 86 St NW
3 rd Wednesday - Central	7:00 pm – 9:00 pm	PAA Edmonton Office – 11209 – 86 St NW
FORT SASKATCHEWAN		
4 th Tuesday	1:00 pm – 3:00 pm	Pioneer House – 10102 - 100 Ave
LEDUC		
4 th Tuesday	6:30 pm - 8:30 pm	Telford House – 4907 - 46 St



AT A GLANCE

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

PARKLAND (SPRUCE GROVE/STONY PLAIN)		
4 th Thursday	10:00 am – 12:00 pm	Stony Plain – 107, 4613 – 52 Ave
SHERWOOD PARK		
2 nd Tuesday	1:00 pm – 3:00 pm	Bethel Lutheran Church – 298 Bethel Dr
ST. ALBERT		
3 rd Tuesday	10:00 am – 12:00 pm	St. Albert 55+ Club – 7 Tache St
WESTLOCK		
Last Monday - (Mar, Jun, Sep & Dec 16th)	1:30 pm – 3:30 pm	Smithfield Lodge – 10203 97 St
GRANDE PRAIRIE REGION		780-882-6640
GRANDE PRAIRIE		
2 nd Wednesday	2:00 pm – 3:30 pm	Grande Prairie Care Centre – 9705 – 94 Ave
LETHBRIDGE REGION		403-317-7710
LETHBRIDGE		
3 rd Thursday	2:00 pm – 4:00 pm	Lethbridge Senior Citizens Org. – 500 – 11th St S
LLOYDMINSTER REGION		780-808-5006
BONNYVILLE		
3 rd Friday	10:00 am – 12:00 pm	Neighbourhood Inn – 5011 – 66 St
LLOYDMINSTER		
2 nd Monday - Care Partners	10:00 am – 11:00 am	Southridge Community Church – 5701 – 41 Street
4 th Tuesday	2:00 pm – 4:00 pm	Southridge Community Church – 5701 – 41 Street
VERMILLION		
2 nd Tuesday - (Jan, Mar, May, Sep & Nov)	1:00 pm – 3:00 pm	Continuing Care – 5720 – 50 Ave
WAINWRIGHT		
2 nd Tuesday - (Feb, Apr, Jun, Oct & Dec)	1:00 pm – 3:00 pm	Wainright Continuing Care – 530 – 6 Ave
MEDICINE HAT REGION		403-526-5521
MEDICINE HAT		
4 th Tuesday	1:30 pm – 3:00 pm	Crossroads Church – 1340 – 22 St SE
RED DEER REGION		403-346-4463
CASTOR		
4 th Tuesday - (Feb, Apr, Jun, Aug, & Oct)	1:30 pm – 3:30 pm	Paintearth Lodge – 4501 – 55 Ave
LACOMBE		
4 th Wednesday (please call for Dec)	10:00 am – 12:00 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	10:00 am – 12:00 pm	Davenport Church of Christ – 68 Donlevy St
ROCKY MOUNTAIN HOUSE		
2 nd Thursday - (Jan, Mar, May, Sep & Nov)	2:00 pm – 4:00 pm	Immanuel Lutheran Church – 5236 – 54 St
THREE HILLS		
1 st Wednesday - (Feb, May, Aug & Nov)	1:30 pm – 3:30 pm	Community Drop In Centre – 414 – 5 St S



CLIENT SERVICES CORNER

Addressing Support Needs in Rural Communities

Written by: Brienne Leclaire



To briefly introduce myself I am Brienne Leclaire. I am the Client Services Coordinator in the Lethbridge Region. I have a Bachelors of Social Work and a background in Neuroscience and Psychology. When I started with Parkinson Association of Alberta I had the chance to spend a few days learning about Parkinson disease, its symptoms and treatment. Those few days do not to compare to the wealth of knowledge I have gained interacting with people with Parkinson's and their families throughout the region.

Outreach is an important part of what Parkinson Association of Alberta does across the province in each of our seven regions. Through outreach, we provide services to rural communities that do not have stationary services. Outreach is mobile. It brings services to where they are needed especially to people who can no longer drive. The Lethbridge Region has always been my home. Being given the opportunity to connect with the communities in my region has been very rewarding because I know, first hand, what it is like to live in a rural community.

The Lethbridge Region received a grant to do outreach in some of the smaller communities across southeastern Alberta. The goal was/is to find people living with and affected by Parkinson's and bring services to these people who may not have (or cannot find) support in their area(s). Currently I am doing presentations in seven communities in southeastern Alberta. These presentations are open to anyone impacted by Parkinson's as well as health care professionals and community stakeholders. They focus on providing information about Parkinson disease and connecting people with Parkinson's and their families to available supports. These presentations help us learn where and what services are needed while simultaneously providing information and support.

My goal as a Client Services Coordinator is to expand the services into these communities. Focusing on establishing support groups and providing supportive counselling in these areas first. Then exploring stakeholders, more education and possible opportunities for programs. In exploring these communities I have gotten to see the uniqueness of each community. For example Pincher Creek has an arts program that is for people who experience pain. The group focuses on expressing through art pain and healing pain. Pincher Creek also runs a cooking class through the Pincher Creek Food Bank. This focuses on cooking healthy balanced meals on a tight budget. Both of these programs are offered by local community organizations and provide unique opportunities for individuals. And, once we know what opportunities are available in a community, I can create partnerships with them to ensure people with Parkinson's and their families have access to services that may benefit them.

Each community is so diverse and being able to connect with individuals and organizations in these communities helps us to understand (on the ground at a local level) what gaps there are, and then determine how we can help get the services Parkinson Association of Alberta provides to these communities in a manner that best fits the community's individual needs. I also get to connect people with Parkinson's and their families with services like the two mentioned above in their communities. Getting to know them, getting to know you, and finding out what might be helpful when you are living in smaller, more rural communities with Parkinson's is my ultimate goal.



Parkinson Association of Alberta would like to take a moment and thank all the walkers, sponsors, family, friends and volunteers who participated in our Flexxaire Parkinson Step 'n Stride walks across the province. It was with your help and support that Parkinson Association of Alberta raised almost \$370,000 through pledges, donations and sponsorships. With over 1500 walkers across Alberta we spent the weekend sharing your stories and spreading awareness about PD!

Thank you Alberta for never turning down the opportunity to Step Up for Parkinson's!
We look forward to seeing you again next year on September 12th and 13th.

PROVINCIAL SPONSORSHIP	\$78,500	GRAND PRAIRIE	\$17,477
CALGARY	\$90,295	LETHBRIDGE	\$14,612
CAMROSE	\$18,875	LLOYDMINSTER	\$21,513
COCHRANE	\$16,801	MEDICINE HAT	\$4,473
EDMONTON	\$81,731	RED DEER	\$24,090
<i>*Totals as of September 30, 2019</i>		TOTAL: \$368,367	



Provincial Sponsor: Flexxaire
Provincial Sponsor: Money Mentors
Trailblazer Sponsors: Save On Foods,
 Totem Charitable Foundation

Pace Setter Sponsor: InterPipeline
High Stepper Sponsors: OneSoft Solutions Inc,
 Nor-Lan Chrysler and Vision Credit
Proud Steppers Sponsors: Crouse's Cleaners, Vision Credit
 Union, Performance graphics, HWD Construction Ltd and
 Two Pharmacy

PLEASE NOTE WE WILL BE ACCEPTING DONATIONS UNTIL DECEMBER 31 FOR THIS YEAR'S WALKS!

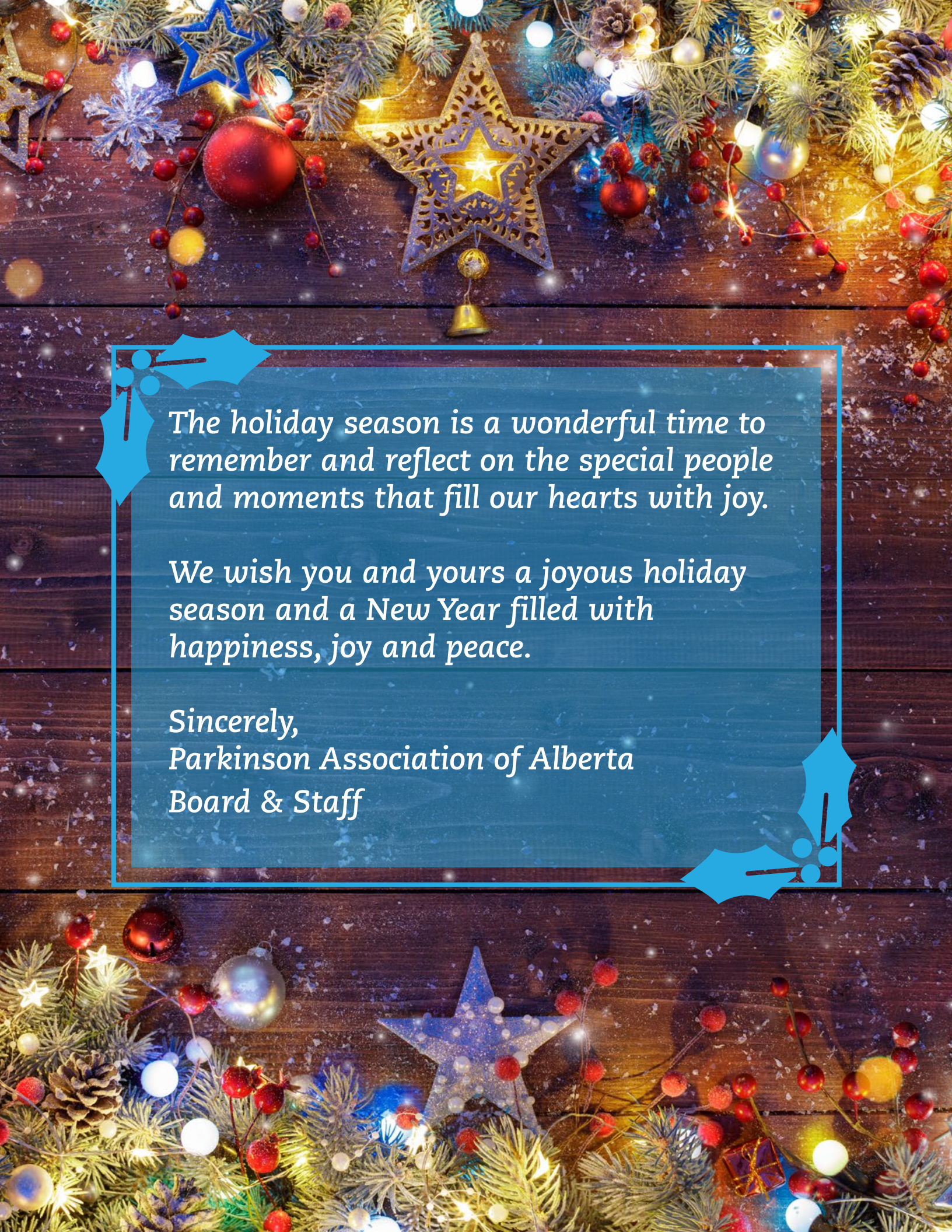


THANK YOU

FLEXXAIRE

SAVE THE DATE
Flexxaire Parkinson Step 'n Stride 2020
September 12th & 13th





The holiday season is a wonderful time to remember and reflect on the special people and moments that fill our hearts with joy.

We wish you and yours a joyous holiday season and a New Year filled with happiness, joy and peace.

*Sincerely,
Parkinson Association of Alberta
Board & Staff*