

# PULSE

Connecting people living with Parkinson disease in Alberta



## **IMPROVING** Communications

# Peer-to-Peer Program

## NOW RECRUITING

Our new Peer-to-Peer Program matches experienced client Mentors with a “MENTEE” who needs a listening ear, understanding of issues stemming from PD, and moral support from a peer who can offer lived experience, personal wisdom and encouragement.



Peer support is done via telephone and can be a one-time conversation or up to six (6), 1 hour sessions.

For more information or to apply to be a a MENTEE, please email [info@parkinsonassociation.ca](mailto:info@parkinsonassociation.ca)



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



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



## Tele-Support Groups



**6** Improving Communications



**10** Keeping the Lines of Communication Open – Helpful Tips for Care Partners



**12** 2019 Flexxaire Parkinson Step 'n Stride

# SUMMER 2019 IN THIS ISSUE...

## Features

- 4 MY STORY**  
Fighting Back Through Boxing – Darcy Henton
- 8 IMPROVING COMMUNICATIONS**  
Communications & Parkinson Disease
- 14 MY STORY**  
Bubby's Story
- 16 IMPROVING COMMUNICATIONS**  
Top 4 Tips for Communicating with Healthcare Professionals

## Every Issue

- 2 CONTACT US**
- 3 FROM THE DESK OF THE CEO**  
A Message from John Petryshen
- 11 RESEARCH IN ALBERTA**  
Champions of Hope
- 15 EVENTS + UPDATES**
- 16 CLIENT SERVICES CORNER**  
Parkinson's in the South East
- 17 AT A GLANCE: SUPPORT GROUPS**
- 19 MEMBERSHIP/DONATION**
- 20 LAST LOOK**  
Why Volunteer for PAA?



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

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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](mailto:communications@parkinsonassociation.ca); or call us toll-free at **1-800-561-1911**.

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.

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*Advertising rates and opportunities are available.*

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



Communication is crucial for any relationship to succeed – be it a relationship with a loved one, a friend, a co-worker and even your healthcare professional.

All relationships have ups and downs. A healthy communication style can make it easier to deal with conflict, build stronger and healthier relationships, and create clear open lines of communication. We often hear how important communication is, but not what it is and how we can use good communication in our relationships.

Communication is defined as the transfer of information from one place to another. In relationships, communication allows to you explain to someone else what you are experiencing and what your needs are. The act of communicating not only helps to meet your needs, but it also helps you to be connected in your relationships.

Unfortunately when you are dealing with Parkinson's the lines of communication can become a little less clear. In some instances it may be difficult to understand what is verbally being said. In other instances it could be difficult to find the right words to say. And in yet another set of instances what people say does not always match their actions. It can be difficult to understand what is really going on or being said when people say one thing but do another.

Non-verbal communication – what is NOT being said -- is just as important as what is actually being said.

With so many different aspects it can leave a person wondering what constitutes good communication? Is it how people speak to one another? Is it about being kind and listening?

The answer is YES. All the above help create healthy, clear, and concise communication. Being able to respectfully speak and listen to one another is what communication is all about.

The theme of this issue is **Improving Communications**. We take a look at not only how to improve communications (**page 06**) but also communications from the perspectives of both a person with Parkinson disease (**page 08**) and care partners/families (**page 10**).

One of the key reasons for communications is to provide information; and we are happy to provide information to you on both research and Flexxair Parkinson Step 'n Stride in this issue as well.

In this issue you will meet Kenneth Murdoch, a PhD candidate at the University of Alberta and a recipient of research funding from the Champions of Hope Campaign. Kenneth fills us in on the research he has been involved in (**page 11**).

You will also find a variety of information about our upcoming 7th annual Flexxair Parkinson Step 'n Stride taking place September 7th and 8th in NINE locations across Alberta! From new additions to the event, to where your money goes, to this years' fundraising incentives; this issue covers a wide range of topics related to Step 'n Stride (**pages 12 & 13**).

**John Petryshen**

CEO, Parkinson Association of Alberta

*Planned Giving*  
...Leave Your Lasting Legacy  
To grow your gift for the next generation call 1-800-561-1911

## Fighting Back Through Boxing

Darcy Henton

### Boxing hooked me at age 60.

I had been diagnosed with Parkinson disease for about a year when I read an article in the Edmonton Journal about people with the disease fighting back through a program at the Avenue Boxing Club.

### Fighting back. The idea appealed to me.

It drew me to a dingy inner-city gym on Alberta Avenue that has become my destination two to three times a week to work out with a decidedly older crowd of athletes with a similar affliction.

When you're tormented by waves of weakness triggered by involuntary shaking, rigidity, fatigue, and difficulty moving, it's amazing how much satisfaction you can derive from pounding away on a heavy bag or loudly smacking your boxing gloves into the padded mitts of a coach or boxing partner.

As boxing greats like Muhammad Ali and Mike Tyson glare down on us from the poster-adorned walls of the club and '70s rock music blares through the speaker system, we sweat through lively workouts guided by professional boxing coaches.

Inspired by the Rock Steady movement that began in 2006 in the U.S., Parkinson Association of Alberta has offered several programs across the province since 2016, starting in Sherwood Park. It is believed, and there are some studies to support it, that non-combative boxing regimens stressing hand-eye coordination, balance, strength and agility help mitigate the debilitating effects of Parkinson's.

Irene Mortensen, 77, a former teacher at the maximum-security Edmonton Institution, says she was looking for an activity that would hone her reflexes and strengthen her muscles when a friend told her about the Avenue Boxing Club program. Mortensen has been working out



twice a week for the past three years. People are often shocked to hear that she is boxing at her age.

"They say: 'What?'" she says, chuckling. "I have to clarify that I'm not boxing people. This is therapeutic boxing. It's not combative boxing."

Kamp believes the program keeps him flexible and slows down the progression of the disease. Besides, he adds, it's a lot of fun.

The boxers encourage and support each other. They joke and tease, drink coffee together after sessions and many participate as a team in the annual Parkinson Step 'n Stride.

"It's a good group of people," says Kamp. "You are exercising with people who have the same monkey on their back. It's a good way to expend a lot of energy, get rid of some frustration and have a good time."

Brian Overland, 50, the youngest boxer in our group, is a former Air Force aircraft technician who has been with the program since it began.



"I really like it," he says. "It's challenging, but in a fun way. I enjoy it because you can give it 100 per cent. The bag doesn't complain when you hit it."

Overland credits the boxing program with not only helping him through Parkinson's, but also with his recovery from a stroke two years ago.

"It helps me concentrate and make sure I get all the movements in, twisting my torso and moving my feet right. The whole coordination thing is what I find challenging, but also rewarding."

Boxing coach Gasper Bonomo, a former World Kickboxing Canadian lightweight and welterweight champion (21-0 record), says the program was launched after Avenue Boxing Club owner Roland Labbe and several boxing coaches approached Parkinson Association of Alberta. Labbe offered the use of the facility free of charge, he says. Bonomo, 59, who has been teaching kickboxing and boxing for more than 20 years, says he uses many of the same routines for the Parkinson's program that he uses to train amateur and professional boxers.

"You work on balance, movement, foot speed, agility, muscular strength and endurance," he says. "It's pretty intense."

In one drill, he calls out rapid-fire numbers that correspond to different punches – jabs, crosses, hooks and uppercuts – that boxers throw at heavy bags in various combinations.

While the boxers don't ever punch each other, they throw a multitude of combinations at padded mitts worn by coaches or pair off with partners and throw simultaneous punches at each other's boxing gloves. They start and end each 90-minute session with a stretching routine and usually do footwork for about 20 minutes. The routine varies from session to session with activities ranging from stretching rubber bands and lifting tires and small weights to throwing punches at stationary pads on the walls or at a rubber boxing dummy affectionately known as Bob.

Mortensen would like to see more people with Parkinson's – especially women – get involved in the boxing program. She says they should not be intimidated by the sport.

"I feel very comfortable coming to the club. Most of the time I am the only woman here, but I think a lot of women would enjoy it."

There is no cure for Parkinson's. It ultimately weakens its victims, atrophies their muscles, shuts down movement and kills them. When Parkinson's-afflicted boxers pound the heavy bag, it's their way of saying: 'Not today.'

Kamp says the best way to fend off the disease is to stay active. Boxing helps him do that.

***"I'll keep on doing as much as I can for as long as I can."***

# IMPROVING Communications

Written by: Brandi La Bonte

Communication, at its simplest, is the act of transferring information from one place to another. It may be vocal, written (ie: books, magazines, websites or emails), visual (ie: photos, maps, charts or graphs) or non-verbal (ie: body language, gestures and the tone and pitch of voice). In day-to-day life it is often a combination of several of these.

Being able to communicate effectively is perhaps the one of the most important of all life skills. It is what enables us to pass information to other people, and to understand what is said to us. With that in mind, I give you the following six tasks...

## Part #1 – Write out the following statements

1. **26 L of the A**
2. **7 W of the W**
3. **90 D in a R A**

## Part #2 – Write out the following words/statements

4.  **AID AID AID**
5. **ABCDEFGHIJKLM  
NOPQRSTUVWXYZ**
6. **TAILR            RIALT  
AIRTL            TLRIA**

The point? Communication without a knowledge base is challenging...not impossible, but challenging.



**Did you know that roughly 60% of Canadians and 88% of Canadian Seniors have low health literacy?**

This means that they struggle to get, understand and/or act upon basic health information due to its complex language and design. This can often be made worse by stress, worry and/or fear of a current or potential medical issue.

Think back to when you or your loved one were first diagnosed. For some, it may have been a relief to have a name for the things they had noticed going on in their own body. But for many, there was shock, fear, sadness and/or anger. Were you in the best headspace to receive information? Did it seem overwhelming? Confusing? Did the words being used seem like a foreign language? Did the doctor maybe even sound like the teacher from Charlie Brown?

Having good health literacy is an important part of communications not only in Parkinson's, but in one's day-to-day life as well.

## What is "Health Literacy?"

Healthy literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services in order to make appropriate health decisions."

- The health literacy of an individual/family is usually negatively affected when they are faced with a difficult impending decision.
- The health literacy of an individual/family can also be negatively affected when they learn some devastating

news, as it can affect how they understand important information regarding the news (ie: prognosis, treatment options, etc).

- Hospitals and medical professionals can drastically improve health outcomes by providing health information in a manner that is accessible and understandable – ie: plain language.

**“Think as wise men do, but speak as the common people do.” - Aristotle**

### What is Plain Language?

Plain language is communication (verbal or written) that the majority of an intended audience can understand the FIRST time they read or hear it.

Plain language is more than just simple words; it is also about providing context and using specific styles of written and/or verbal communication. Consider the following example...

**Let us ponder the reasoning behind the feathered barnyard fowl utilizing forward motion to meander over the automobile pathway.**

It is a whole lot clearer and to the point to simply ask...

**“Why did the chicken cross the road?”**

It is good to remember that people absorb information differently – for some it is listening, for some it is reading and for others still it is visual. A few points to consider when communicating in plain language are:

- Use the simplest word(s) to state what you mean. If a simple word is not available then be sure to explain what is meant.
- Try to avoid using acronyms and jargon.
- Use verbs – an active voice is clearer and easier to understand than a passive voice.

#### TASK ANSWERS:

1. Twenty-six letters of the alphabet
2. Seven wonders of the world
3. Ninety degrees in a right angle
4. First aid
5. Missing You/The only thing missing is you
6. Trail mix



### Listening vs Hearing

Hearing is the physical ability, while listening is a skill. Listening skills allow a person to make sense of and understand what another person is saying. To really listen is one of the key components of good communications. A good communicator listens with their heart and eyes as well as their ears. They are able to read between the lines of what is being said (or not said) and interpret unspoken, non-verbal communications.

Listening involves more than just hearing what is being said and not everyone knows how to be a good listener.

- Maintain eye contact with the speaker.
- Drop preconceived notions and assumptions and adopt an attitude of being open to information.
- Do not interrupt the speaker; wait until he/she is completely finished, then ask questions.
- Control body language. As much as possible, sit still while listening.
- Look for nonverbal cues such as facial expressions and posture to get the full understanding of what the speaker is saying.

The importance of effective communication skills for people with and without Parkinson's cannot be overemphasized. Most aspects of day-to-day life involve two-way communication – speaking and listening. Improving this skill set can lead to stronger, healthier relationships and less stress overall.

*It is our hope that you find this (and other issues) informative, beneficial and helpful. We welcome your comments, feedback and suggestions at [communications@parkinsonassociation.ca](mailto:communications@parkinsonassociation.ca)*



# Communications & Parkinson Disease

Written by: Brandi La Bonte

**As people age into their 60s and 70s, their voices start to change. Vocal folds weaken, cartilage in the larynx begins to harden, and the respiratory system (which helps power the voice) begins to work less efficiently. One’s voice may start to sound breathy, uneven or hoarse. There are added challenges in terms of voice and speech when one also has Parkinson disease – these challenges present themselves in both motor and cognitive function.**

Parkinson disease affects the body’s motor system, which means it affects the voice as well. From the diaphragm to the larynx to the face itself, a multitude of muscles are used in speaking. Though symptoms vary widely from person to person, the speech and voice symptoms most commonly demonstrated by people with Parkinson’s are:

- **Reduced vocal loudness (soft voice or hypophonia)**
- **Monopitch (lacking the normal variation in inflection)**
- **Disruptions of voice quality**
- **Abnormally fast rate of speech**

This cluster of symptoms is often termed “hypokinetic dysarthria”.<sup>1</sup> These issues can happen at any time and tend to increase as Parkinson’s progresses.

When it comes to speech/language and cognitive function, the following areas are typically affected by Parkinson disease:

## Bradyphrenia

Meaning “slow brain”, bradyphrenia can be best explained as slow mental processing. This phenomenon can generally impact the speed at which information and language can be recalled and/or processed; this can result in difficulties in switching from one task to another, taking part in conversation and problem solving.

## Memory

Includes recalling information, learning and retaining new information. People with Parkinson disease

can experience difficulties in recalling information/memories, but in general, this function is less impaired than in those with Alzheimer’s disease. When given cues and/or choices, people with Parkinson’s frequently are able to recall more information.

## Language

Includes difficulty finding the right word(s), feeling tongue-tied, naming objects, verbal concepts and comprehension. The most common language-related problem is word-finding; that is knowing what you want to say but having difficulty “finding” the right word or words to use.

## What Can Be Done to Improve and Maintain Communications?

While not everyone diagnosed with Parkinson disease experiences challenges with communication, for those who do it can be a significant problem that can lead to stress, anxiety and even social isolation. This does not mean however that there isn’t something one can do to help improve and maintain good communication for as long as possible.

Speech Pathologists (also called speech therapists) can be helpful for those experiencing communication challenges; they can also help with swallowing issues!

If one does not have access to a speech therapist there are many other alternatives available. To improve and maintain a good speaking voice it is good practice to do vocal exercises twice per day for best results.

Here are a few techniques that can be undertaken:

## Vocal Exercises

- Sit or stand tall & then inhale through the nose, feeling the ribs and belly expand as the lungs fill with air.
- Continue to take several deep breaths from the diaphragm (the large main muscle located at the base of the lungs that plays a vital role in the breathing process).
- Exhale gradually through the mouth as if blowing out a candle.
- Take a deep breath and then push from the diaphragm and say, "AHH" for minimum 15 seconds. Repeat the process using the sounds -- "OH", "OO", "EE" for at least 15 seconds each.
- Next, take a deep breath and as the breath is released alternate between a low pitched "OH" and a higher pitched "EE" for 30 seconds.

Yes	Nurse	Doctor	Carer	Walking Frame	Wheelchair	No
Medicine	Pills	Bathroom	Bed	Toilet	Bath	Shower
Bedroom	Hot Drink	Cold Drink	Food	Help	I don't understand	Slippers
Light	Sit up/down	TV	Telephone	Newspaper	Walk	Teeth
Glasses	Clothes	Bag	Walking Stick	Shopping	Cold	Hot
Alone	Husband/Wife	Family	Garden	Noise	Hearing Aid	Watch
Hairdresser	Priest/Vicar	Worried	Pain	Bored	Tired	Angry

A	B	C	D	E	F	G	H	I
J	K	L	M	N	O	P	Q	R
S	T	U	V	W	X	Y	Z	

1	2	3	4
5	6	7	8
9	0		

**To work on volume.** Take a deep breath and say the names of the days of the week as loud as possible. Repeat with the months of the year, the alphabet, and counts from 1 to 20.

**Practicing simple tongue twisters can help improve the ability to speak clearly and provide a quick cognitive workout. Start slowly and build up speed over time.**

- The blue bird blinks
- Three free throws
- She sells seashells by the seashore
- Read out loud, in a loud voice using expression (ie: if there is a question or exclamation, reflect that in the voice)

**Sing!** Either as part of group or individually. Research indicates that singing can help improve communication in people with Parkinson disease.

**Good communication** can happen when one is relaxed and takes the time to speak slowly and clearly

When possible, **plan important conversations** during medication "on" times. If people have difficulties understanding you, the following approaches may help:

- Take a deep breath, relax and speak loudly and slowly; remember it is not a race
- If writing is not an issue, carry a paper and pen as a back up
- If writing is an issue, trying using an alphabet or common word/phrase board to help by spelling out words and/or identifying phrases/questions by pointing (as above)

Working at improving communication is important not only for the management of one's Parkinson disease, but also for keeping relationships strong and combating social isolation.

### References:

1 Darley FL, Aronson AE, Brown JR. *Motor speech disorders*. Philadelphia: W.B. Saunders Company, 1975.

## Keeping the Lines of Communication Open – Helpful Tips for Care Partners

Written by:  
Brandi La Bonte



Open, honest communication is a part of every healthy relationship. Unfortunately, as Parkinson's progresses communication is one of the key areas affected. Voice and speech problems, deteriorating facial expressions and cognitive issues all contribute to communication challenges. This can lend itself to a situation where both parties have the desire to communicate but their abilities simply do not align.

The good news is there are things you can do as a care partner/family member of a person with Parkinson disease to improve communication and decrease stress.

If you're speaking to someone with has Parkinson's disease, keep these tips in mind:

- **Be patient, speak clearly and calmly and allow enough time for your loved one to reply.**
- **Create a positive atmosphere. Hold conversations at eye level and make eye contact during conversation. Sit down if the person with Parkinson's is sitting, and assume a relaxed posture to convey your patience and willingness to listen.**
- **Limit distractions and noise – including tv, radio, cell phones and too many people in the room.**
- **Support and reassure your loved one throughout the conversation. Give feedback such as a nod of the head or a "yes" or "I see" to indicate that you understand what he/she is saying.**
- **Avoid finishing sentences for someone with Parkinson's unless asked for help finding a word or phrase.**
- **If you cannot understand what was said, ask the person for clarification or to repeat; if you pretend to understand in order to save time, misunderstandings can result. Also, the person with Parkinson's may not make as much of an effort to speak clearly if he/she thinks you understand.**

- **Do not say you understand when you really don't. Repeat any part of the statement you did understand and ask for clarification or repetition of the rest. Asking for a repetition of a phrase may result in clearer pronunciation the second time around.**

- **Ask questions that:**
  - **require yes/no answers. Ie: instead of asking, "What would you like to eat?" ask, "Would you like pancakes?"**
  - **offer two choices when you ask a question. Ie: "Would you like soup or a sandwich for lunch?"**
- **Use gentle prompts before beginning a new topic of conversation. Ie: "Let's talk about the kids." And, when you change the subject, use similar cues Ie: "Let's talk about the garden now".**

As Parkinson's progresses there may come a time when cognitive issues present a larger problem and verbal communication is no longer ideal or possible. This can be especially difficult for both parties. A few things to remember:

- **Do not assume your loved one cannot understand what is being said. Never say anything you would not want your loved one to hear.**
- **The power of human touch is undeniable. Human touch has long been known to have soothing, healing qualities, especially for those who are unable to communicate using traditional methods.**
- **Look for subtle changes in behavior, breathing and posture to see what you should continue or what you should change.**

Communicating isn't always easy; and when your loved one has Parkinson's it can be even more difficult. While your approach to communication will need to change as the disease progresses, there are ways to help you maintain open lines of communication with your loved one. It just takes patience and practice.



# Champions of HOPE

In this edition we speak with Kenneth Murdoch, a PhD candidate at the University of Alberta and a recipient of research funding from the Champions of Hope Campaign.

**M**y name is Kenneth Murdoch, and I am a PhD candidate at the University of Alberta. I am the fortunate recipient of a Graduate Research Scholarship from Parkinson Association of Alberta through the Champions of Hope campaign. I am enormously grateful to the Parkinson Association of Alberta for providing me with the opportunity to research Parkinson disease.

In the first year of my tenure with this grant, I have met many of the dedicated professionals conducting PD research, and this experience has been truly invaluable. I have also made a concerted effort to do high-quality research while translating knowledge from psychology to professionals in movement disorders, neurology, and the broader community.

Over the last several years, I have spoken to many people with Parkinson disease, and I have been privileged to hear the inspiring personal stories of people reconnecting with hope in the face of a Parkinson disease diagnosis. These stories have deeply impacted me and have driven me to learn more about the lived experience of people with Parkinson's.

In the last year, I designed a qualitative study to explore the lived experience of hope for those recently diagnosed with Parkinson disease.

By listening to the stories people tell and strengthening the voices of people with Parkinson's in academic research, I aim to provide health professionals with an in-depth understanding of the vulnerable experience of adjusting to a diagnosis of Parkinson disease and also explore the significance of hope throughout this experience. This research is intended to develop our understanding of how people stay engaged with life in the face of a Parkinson disease diagnosis. I also anticipate that my research may provide clinicians with innovative approaches to access, promote, and encourage hope in people with Parkinson's.

Most of my research focuses on "positive psychology." Positive psychology is a unique research topic focused on developing an understanding of human flourishing through building upon the strengths, capabilities, and assets people have.

Over the last three years, I have been working closely with Dr. Janis Miyasaki, Dr. Denise Larsen, and a team of researchers at Hope Studies Central at the University of Alberta to explore the effectiveness of a positive psychology group for people with Parkinson disease. This research aims to provide more avenues of support for people with Parkinson's and promote well-being in their lives.

In the coming years, I look forward to working closely with the Parkinson Association of Alberta and learning more from the people affected by Parkinson disease.



FLEXXAIRE

PARKINSON



Step 'n Stride™

**We encourage YOU to Step Up for Parkinson's on September 7th and 8th and join individuals, families, neighbors and friends at one of NINE locations across Alberta to celebrate as a community and take action at the 7th Annual Flexxaire Parkinson Step 'n Stride™, Alberta's largest Parkinson disease fundraising event!**

As a leader in pursuit of a better today and tomorrow for those living with and affected by Parkinson disease and Parkinson's Plus Syndromes, Parkinson Association of Alberta plays a critical role in addressing the needs of the Parkinson's community. By participating in and/or supporting Step 'n Stride, you are helping to ensure we can continue to deliver vital support and services to all Albertans as well as aim for a brighter future through research.

## NEW THIS YEAR - Walking "In Memory"

This year we will be adding an "In Memory" component to all the walks. We would like the walks to symbolize hope, be a time of celebration and remembrance. Participants will be able to have a moment of silence in memory of a loved one. We are asking any of those who wish to take part in this special component to the walk to reach out to your local representative. We are looking for members of PAA to send in a photo and write up in memory of their loved one.

## Where Does the Money Go?

In 2018 we earmarked 9.5% of revenues for research; and committed 44% of revenues directly towards Client Services – including our no cost "core services" - supportive counselling, support groups, education, referrals, information and resources. The money YOU raise in your Region is allocated directly to those core services in YOUR Region as well as a portion towards research.

In 2018 this included (but was not limited to):

- **439 new clients and 8409 people served via support services and outreach**
- **40 support groups across Alberta and 13,070 minutes of supportive counselling provided**
- **7 graduate students and post-doctoral fellows awarded research funding**

## How to Fundraise

It's not too late to get started! Here are a few tips from other successful fundraisers to get your fundraising off the ground.

- 1) Announce it on Facebook so there's no backing out!**
- 2) Donate to yourself and set an example for others to follow.**
- 3) Ask people to donate to you by sharing your online fundraising page.**
- 4) Get ideas from the fundraising tools and start getting creative!**  
(This list can be found on our website: [parkinsonassociation.ca/stepnstride](http://parkinsonassociation.ca/stepnstride))
- 5) Share your story on your fundraising page, why are you walking? Why do you fundraise? Adding a personal touch encourages people to give more.**

**Visit [parkinsonassociation.ca/stepnstride](http://parkinsonassociation.ca/stepnstride) to login and get started today and thank you for stepping up for Parkinson's!**

# What to Bring on Walk Day

Your pledges (cash and cheques), your print off of any online fundraising forms, comfortable walking shoes and, of course, your friends and family! Please check with your Regional Office to see if your Walk site is a pet-friendly one. Don't forget weather appropriate items like sunscreen and a hat or an umbrella and jacket.

PAA is always looking for volunteers to help out! Volunteer forms are located on our website under the "Get Involved" tab – <http://parkinsonassociation.ca/volunteer> or contact your local representative to see how you can get involved.

# Want to help out?

Every registrant will receive a Flexaire Parkinson Step'n Stride™ toque!



\$250  
Tech Shirt



\$500  
4GB USB



\$5000  
Soft Navy Blanket



\$1000  
Non-tip Travel Mug



\$2500  
Portable Juice Blender



## SATURDAY, SEPTEMBER 7

### CALGARY

South Glenmore Park  
Registration: 9AM

### EDMONTON

Rundle Park (Family Ctr)  
Registration: 9AM

### GRAND PRAIRIE

Muskoseepi Park Pavillion  
Registration: 10AM

### LLOYMINSTER

Bud Miller Park  
Registration: 9AM

## SUNDAY, SEPTEMBER 8

### CAMROSE

Jubilee Park  
Registration: 1PM

### COCHRANE

Mitford Park  
Registration: 12PM

### LETHBRIDGE

Henderson Lake Park  
Registration: 1PM

### MEDICINE HAT

Kin Coulee Park  
Registration: 10AM

### RED DEER

Golden Circle Sr Ctr  
Registration: 9AM

## Bubby's Story

Written by: Lori Williams, President of ROAR Organic



**E**arlier this year, when I was asked if ROAR Organic would be interested in being the drink sponsor for Alberta's Flexxaire Parkinson Step 'n Stride, with no hesitation I said yes.

This was not only from a health perspective - as I know ROAR Organic is a clean, pure and all natural hydration beverage beneficial for keeping patients hydrated - but also from a personal perspective, as I witnessed firsthand when I was younger the profound impact Parkinson's had on my family.

My grandmother, Esther, known to me as "Bubby" - picture a blonde, tall, strong, hard headed, too smart for her own good, Polish woman - had Parkinson's.

Bubby noticed her hands starting to shake when she was in her late 60s, early 70s. By the time she hit 80, the shakes were uncontrollable and she could no longer function on her own. Without the means to hire help, at the age of 85, my overly fit and healthy grandfather ("Zaide") took it upon himself to be the arms and legs for my Bubby.

For 2 years, he dressed her, fed her, bathed her, carried her, and made her as comfortable as she could be in her own house. The day she fell off her chair and hurt her

hip was devastating. My mother tells me Zaide called her frantically crying "I only looked away for 5 minutes. We are in the hospital. I can't care for her anymore."

Bubby ended up in the St Mary's geriatric ward for three years as she waited to be placed in a facility that could care for her. Her time in the hospital are my last memories of time spent with her. Her legs frail and skinny, shiny from the baby oil they put on them, mostly exposed as she sat in a wheel chair in front of me asking how school was, could I bring her Kentucky Fried Chicken (lol!) and how is my sister treating me.

While Parkinson's had continued to devastate Bubby's body and mobility, her brain was still sharp as a tack. She still could give me the same stern frowning and lecture if she felt I was short with her or not paying attention!

Zaide spent three years of his life in St Mary's caring for Bubby. St Mary's was very good to her and a specific nurse became not only her care giver, but her family. When a space opened up at Maimonides, a geriatric home in a Jewish neighbourhood in Montreal, Bubby was devastated. She was close to 85 and felt at home at St Mary's. It was an hour commute for Zaide and the nurse that became her family, could only visit once in a while. When she arrived at her new facility, Bubby changed. She stopped talking, stopped smiling, and it was not long before she made the mental decision this is not how she wanted to live anymore.

My grandmother passed away after refusing all forms of food and care for 30 days. In a matter of less than a decade, Parkinson's had transformed a strong, vivacious woman, who walked miles every day, to a patient in a hospital unable to get out of her wheel chair.

Bubby is one of many stories of people impacted by the disease. I am proud to have ROAR Organic sponsor the Flexxaire Parkinson Step 'n Stride™ and hope the money raised can further research and care provided by Parkinson Association of Alberta.

# EVENTS + updates

## UPCOMING EVENTS *For more information on our upcoming events, please visit our website at [www.parkinsonassociation.ca](http://www.parkinsonassociation.ca)*

### Flexxaire Parkinson Step 'n Stride™ 2019

Nine walks across the province taking place on September 7 & 8! To stay up-to-date check out our website at [parkinsonassociation.ca/stepnstride](http://parkinsonassociation.ca/stepnstride) or follow us on social media! **Our provincial goal this year is \$440,000!** Online registration is open! Register as an individual or team today!

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

**Monday, September 9 – Windermere Golf and Country Club - Edmonton**

Planning is in full swing so come join us on the course all "fore" a great cause! Spots are still available – register as an individual or team! To register or for more information call **1-800-561-1911** or check out our website [parkinsonassociation.ca/markmerciergolftournament](http://parkinsonassociation.ca/markmerciergolftournament)

### Tap'd Out Food + Beverage Festival

**Monday, August 12 – Red Deer**

Who brewed it best?!? We invited 12 breweries from across Central Alberta to take part in a fun competition! On June 27 we gave them each a secret ingredient – pureed haskap berries from North 49 Fruit Corporation. Each brewery took the secret ingredient back to their brewmaster to make a special beer that was tasted by 100s of guests and judged by celebrity judges.

Watch for more Tap'd Out events on our website and social media platforms. Upcoming events are being planned for Calgary, Cochrane and Medicine Hat.

### 28th Annual Parkinson Tulip Golf Tournament

**\*\*NEW DATE\*\* Monday, September 16 – Calgary**

Rain, rain and more rain kept golfers from enjoying a day on the course in support of Parkinson's on July 4. The good news is we have rescheduled! Join us all "fore" a cause on September 16, 2019 at Silver Springs Golf & Country Club. Spots are still available to register. Register online ([parkinsonassociation.ca/tuliptournament](http://parkinsonassociation.ca/tuliptournament)) or call us toll-free at **1-800-561-1911**.



### Huge Thank You to our sponsors and on hole activities:

Coupland Kraemer Architecture + Interior Design Inc., Legacy Wealth Management, Northwest Acura, Valentine Volvo, Expedia Cruise Ships, Blaskin & Lane Tire Centres, Service Master, Gold Point Petroleum, Nanton Water, Made Good, ROAR, Blackfly, Steamwhistle, Burwood Distillery, Just Me Production, PM Gigs, Pilots Friend, Eau Claire Distillery, Last Best, Flair Graphics & Printing Ltd, Elevate Auctions, Silver Springs Golf & Country Club, Stardust Event Group and Spolumbo's Fine Foods & Deli.

## PAST EVENTS

### A Diamond Evening

On May 24 the music of Neil Diamond filled the air in Medicine Hat! Special thanks to: Jim Pattison Broadcast Group, CHAT News Today, CHAT TV, Roset by Reid and the Days Inn Medicine Hat.

### CLIENT SERVICES CORNER

# Parkinson's in the South East

Written by: Amanda Sears



It is a great privilege that I get to introduce myself and talk about all of the amazing people and what we do in my region. I am Amanda Sears, the Client Service Coordinator for the Parkinson Association of Alberta in the South East. My region covers a couple of great cities, and many small towns. Sometimes we miss the services of the bigger centers but overall, we look out for one and other and make sure we have the best care possible.

I love working with people and hearing their stories about what makes them who they are. This passion naturally lead me to a great career in Social Work where I can meet people who are working hard to sort the cards they have been dealt, to live well.

My region has many great strengths. It is very clear that the people in my area really like meeting as a group and find that the connection and conversation of the support group very useful to them. We continue to run three, tight committed groups that work hard to create an atmosphere of love and support. We welcome anyone new that would like to talk, learn about their disease or just get out of the house and we are hoping to reach out and connect with those that are facing Parkinson Disease alone and invite them to meet with us.

The Medicine Hat Region, has a home based office which has offered so many benefits in supporting the clients. As many clients in the region don't drive and other forms of transportation are limited, I am able to have a traveling office and meet clients in their home. Going into a client's environment to see a major part of their personality, what's important to them and how they live offers me so much information as to who they are, what they value and what their needs are. It's also fun to meet a client in the community. Having a coffee at their favorite shop, going for a walk or hanging out at the library tells me a lot about them as well.

The current set up of the Parkinson Association has allowed me to make some great friends in the community to help support the work we do in our area. I have connected with many businesses that support the Parkinson Association through education, awareness and services to clients. The South East corner of the province is full of people determined to make sure everyone living with Parkinson Disease does not fight the disease alone.

#### **TOP 4 TIPS FOR COMMUNICATING WITH HEALTHCARE PROFESSIONALS** *Written by: Brandi La Bonte*

**BE PREPARED** – Consider making a list of the questions and/or items you would like to talk to your healthcare professional about. If there are more than one, consider ranking them in order how much they are troubling you. Bring a pen and paper so you can write down what your healthcare professional tells you. You may also want to consider bringing a loved one.

**SHARE INFORMATION** – tell your healthcare professional about any current concerns you are having. Be brave! Health issues can be hard to talk about, but it is important to provide as much relevant information as possible. If your healthcare professional does not specifically ask for information you think is important, tell them.

**ASK QUESTIONS** – If you do not understand what is being said, it is ok to ask for an explanation or to have it described in a different way.

**GET IT IN WRITING** - Ask your healthcare professional to write down what you should do between now and your next visit. This may include instructions for how to take medications, actions you should take, and/or lifestyle modifications.

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



## AT A GLANCE

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

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

# FOLLOW US



/ParkinsonAssociationofAlberta



@PDAssocAB



parkinsonassociationofalberta





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

## Personal Information

Mr.  Mrs.  Miss  Dr.

First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Prov: \_\_\_\_\_ Postal: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Person Living with PD  Spouse/Partner has PD  Family Member/Friend  Professional Health Provider

I would like to learn more about volunteering

I would like to receive email communications from Parkinson Association of Alberta (including newsletter, updates & information)

## Membership

Membership is \$25 annually and runs from January 1 to December 31.

I wish to BECOME a member  I wish to RENEW my Membership

I would like my Parkinson Pulse Magazine mailed to me

## Donation

Donations of \$20 and up will be receipted.

I wish to make a DONATION in the amount of: \$ \_\_\_\_\_

In Memory of \_\_\_\_\_  In Honor of \_\_\_\_\_

Please send a notification of this gift to (name and address): \_\_\_\_\_

## Payment

Enclosed please find my cheque (made payable to Parkinson Association of Alberta)  
or cash for \$ \_\_\_\_\_

Please bill my:  Visa  Mastercard  American Express

Name on Card: \_\_\_\_\_

Card Number: \_\_\_\_\_ Expiry: \_\_\_\_\_ CVD: \_\_\_\_\_

# Why Volunteer for PAA?

Written by: Wendy Porter

**P**arkinson Association thrives as a result of the number of volunteers who come forward to support our programs, our conference, our support groups, and our walk and other events. Volunteering makes for wonderful opportunities to meet new people, learn new skills, and connect with others through the contribution of time and the sharing of talents. For some people, it offers the chance to give something back to the community or to fill a void.

For Jean Barr, it became her way to not only fill a void in her community but something she felt the need to do for others. Her husband had just been diagnosed with Parkinson disease and neither of them felt that they had the education or support to know how to live well with the disease. They attended the Red Deer Support group to hear a presentation from a local neurologist. Jean advised that she knew her husband's ability to travel with Parkinson's would become more and more difficult and the winter roads always added an extra challenge that she knew they didn't need. In 1992, Jean found a location in Three Hills and began recruiting speakers from her community to educate herself and others living with and affected by Parkinson's and founded the Three Hills Parkinson Support Group.

Arriving at the Three Hills Support Group was like going home for a visit. Jean met everyone with a smile on her face, coffee and tea were ready to go and a special snack. When asked why she continued to volunteer with the support group after her husband passed away, Jean replied, "Because it's what you do." "You give back to the people who helped you." Unfortunately, we lost Jean in May of 2019.

With busy lives it can be hard to find time to volunteer. Labour Standards reports that volunteers are at the lowest rate since 2002 – showing a decline of 25.4 %. Some suggest that the decline is in part due to the struggling economy; people are focused on getting and maintaining paid work. However, the returns and perks of volunteering often outweigh the time you invest.

**1.** Volunteers live longer and are healthier. During later life, volunteering keeps you physically active, gives a

robust psychological well-being and people report feeling happier and healthier.

- 2.** Volunteering establishes strong relationships. A 2010 AARP study reported the prevalence of loneliness is at an all-time high – 1 in 3 adults over the age of 45 categorized themselves as lonely. Volunteering alongside people who feel as strongly as you do about supporting a particular cause creates a path to develop strong relationships and volunteering alongside family can strengthen family bonds based on "doing" your values. These benefits have a ripple effect – Children, grandchildren, nieces and nephews who volunteer alongside you often go on to volunteer as an adult.
- 3.** Volunteering is good for your career. People who volunteer often find employment easier because of the relationships that are made. It's always helpful to have an edge – to know someone who knows someone – when a job that interests you comes up.
- 4.** Volunteering is good for society. Parkinson Association, like most mission-drive charitable organizations, is successful because volunteers are able to help support the work that is being done – ensuring the success of the organization enabling it to carry on supporting people who rely on the services.
- 5.** Volunteering gives you a sense of purpose. Volunteers often express a need to serve. The very nature of volunteering – choosing to work without being paid for it - carries with it a satisfaction that money can't fill. We often hear, "*It warms my heart to see...*"

If you aren't currently volunteering with Parkinson Association of Alberta we have many ways for you to become involved. Your passion, your expertise, your time, will all be put to good use as we move forward during the tough economy to try and support the 10,000 people diagnosed with Parkinson disease and their families. Check out our website <http://parkinsonassociation.ca/volunteer> or call **1-800-561-1911** for more information as not all of our opportunities may be listed.

15TH ANNUAL

# 'Mercier Shanker'

GOLF TOURNAMENT



MONDAY, SEPTEMBER 9TH

WINDERMERE GOLF & COUNTRY CLUB, EDMONTON AB

PROCEEDS SUPPORT



11:30am	Registration
12:00pm	Lunch
1:30pm	Shotgun Start
6:30pm	Dinner

To register please visit:

[parkinsonassociation.ca/markmerciergolftournament](http://parkinsonassociation.ca/markmerciergolftournament)

Call: 1-800-561-1911 Email: [info@parkinsonassociation.ca](mailto:info@parkinsonassociation.ca)

*All "fore" a cause...*

## 28TH ANNUAL PARKINSON TULIP GOLF TOURNAMENT

**POST-PONED TO DUE TO RAIN**

NEW DATE:

MONDAY, SEPTEMBER 16, 2019

SILVER SPRINGS GOLF & COUNTRY CLUB - CALGARY, AB

Limited spots available, register your foursome today!

[PARKINSONASSOCIATION.CA/TULIPTOURNAMENT](http://PARKINSONASSOCIATION.CA/TULIPTOURNAMENT)

OR CALL (403-243-9901)



FLEXXAIRE



**Step 'n  
Stride**

STEP UP FOR PARKINSON'S

# SEPTEMBER

# 7<sup>th</sup> & 8<sup>th</sup>

Join walkers in Alberta as they support Parkinson Association of Alberta and our mission to make every day better for Albertans affected by Parkinson disease. There are nine Walk locations across the province.

**BBQ \* ENTERTAINMENT \* FAMILY FUN \* WELLNESS FAIR \* AND MORE!**



For more information:

1-800-561-1911

[parkinsonassociation.ca/stepnstride](http://parkinsonassociation.ca/stepnstride)



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