

# Parkinson's Post



Supporting people  
with Parkinson's  
since 1991

March, 2019 • Inside this Issue

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## From The Board

**First, we would like to welcome** to our board a new director—Cindy White. She and her husband, Alan, joined our support group in 2016. They are winter residents and spend their summers in Maine. Cindy already serves on our newsletter staff, answers the emails received at the address given at the bottom of this page, and assists board members in other ways.

There are more openings on the board and committees. If you have technology, organizational or public relation/marketing skills and want to share them with our support group, PLEASE speak with one of our board members listed on the calendar page of this newsletter. If you enjoy talking with people on the phone or planning social events, we need you! If you have ideas for activities for SAC Club, let us know!

\*\*\*\*\*

It's hard to believe that this month's lecture is already the last in the current series. We are excited to have a new speaker and new topic (hearing loss). Soon we will be planning our next lecture series that will begin in September. I bet you have ideas for topics and maybe even suggestions for speakers. Consider joining the lecture committee when we announce a meeting date. New ideas are appreciated.

\*\*\*\*\*

Check out the March schedule for SAC Club. Often, additional activities and discussions will be added after the newsletter is printed. Just drop in on Mondays to see what is happening. Remember the option of riding the Sun Shuttle. You can arrange rides from your house to Friends in Deed and back home by calling 520.792.9222 in advance. The shuttle has a lift that can handle wheelchairs and walkers.

*Stay active!  
Charlene*

## March Lecture



**Like last month**, the March lecture will be on the 1<sup>st</sup>. Be prepared or you will miss it!

The presenter will be Laura M. Vitkus, MPH (Master of Public Health). Her title at the Arizona Center of Aging is Program Coordinator for AZ-Geriatrics

Workforce Enhancement Program. She will be presenting "A Conversation about Hearing Loss and More."

Why hearing loss?

- Perhaps you and your partner have debated whether your difficulties with conversation are due to the Parkinson's soft voice or the partner's hearing loss.
- Did you know that there is a link between hearing loss and dementia? Parkinson's often causes cognitive changes. Hearing loss can worsen cognitive skills because it interferes with sensory input to the brain.
- One of our support group's goals is to stay socially connected. Hearing loss makes socializing difficult.

Laura's expertise extends beyond hearing loss so she may address other subjects, such as oral health and fall risk.

*Stay Alive*

*Charlene*



## Did You Miss It

### SAC Club Grand Opening

"If you build it, they will come." You probably recognize the line from the movie *Field of Dreams*—or maybe I'm the only one that remembers it because John and I lived an hour from the baseball field built in an Iowa cornfield and used during filming. We didn't build Friends in Deed, but SAC Club is the result of a dream for a place to gather and people did come.

Those who attended the grand opening had a chance to do brain exercises, work on a jigsaw puzzle, construct plastic figures, eat, and play games (that's a fact—no crap). The activities at the grand opening were a sampling of what the club will continue to offer on Mondays at 1:00. Each week will be different.

Thank you to our volunteers who made the grand opening possible. Also, thank you to the volunteers from Access/Wisdom Eldercare, Home Care Assistance of Green Valley, HomewatchCareGivers, and Southern Arizona Eldercare, who did more than assist.

We had a dream, we built it, and we hope you will keep coming. --Charlene

### Discussion Group

**What are the "Five Wishes"** we are talking about? Can you list them?

We held the first of what may prove to be three or more sessions on "Five Wishes" and eventually "The Conversation" on Monday, February 4. The "Five Wishes" is a nationally known and copyrighted recognized statement of an individual's very personal and clear wishes about his or her final hours on earth.

While death is inevitable, we can and should set forth how we are treated during those final hours and the preparation of such legal and medical phases are within our capability IF—and only IF—the proper steps are taken. The discussions on Feb. 4 addressed those points and laid out the necessary steps to be taken in the initial preparation of the "Five Wishes" documentation.

While there were over 25 participants in this initial session, if there is sufficient interest, we will host another session for those who either missed the Feb 4 presentation or who wish to expand their knowledge of the "Five Wishes" program. If you are interested in attending a session on the "Five Wishes," please let Bill know.

Oh, yes...the "Five Wishes" are:

1. Who do I want to make medical decisions for me when I can't?
2. What kind of medical treatment do I want or not want?
3. How comfortable do I want to be?
4. How do I want to be treated?
5. What do I want my loved ones to know?

--Bill

### February Lecture

It's a good thing that our presenter, Maria Christina Ospina, MD, speaks fast because the large crowd had a lot of questions for her, particularly about medications.



One of Dr. Ospina's favorite sayings is *Parkinson's is the poster child for body/mind connection*. She reminded us that doctors diagnose the disease from motor symptoms, but the nonmotor symptoms may appear 20 years earlier.

She explained that Parkinson's is usually treated with a cocktail of medications including levodopa, agonists, and MAO-B inhibitors. The goal is to give the brain a steady dose of dopamine and so she likes extended release medications or the pump delivery of levodopa. With the pump, it's not necessary to take a cocktail of meds.

Dr. Ospina is a neurologist and movement disorder specialist. Though her main practice is in Phoenix, she now works at Banner in Tucson twice a week. She is taking new patients. She also has telemedicine patients; however, people living in Green Valley do not qualify for Medicare coverage for telemedicine because it is not considered a rural area.

You can find more of Dr. Ospina's talks on You Tube. Enter "PMDAlliance" into You Tube's search window.

### **MORE FROM Dr. O on P3**

#### ***Parkinson's Post***

**Editor:** Dan Fahy **Contributors** **Writers:**  
**Proofreaders:** Cindy White **Bill Hanne**  
**Layout:** Dan Fahy **Charlene Ostlund**  
**Sue Colley**

*Thank you to these volunteers who made this publication possible.*

## More News



**Mondays 1:00 – 3:00; Come & go as you please**

March 4: Rut-Breaker Adventures, Scattergories (a game), art project by Home Care Assistance

March 11: Assemble a remote-control vehicle, brain exercises

March 18: Card making, Rut-Breaker Adventures

March 25: Make & take with Janice, Rut-Breaker Adventures

Scheduled events are subject to change. Drop by each week to see what is happening. Some activities are available every week, such as, puzzle books, jigsaw puzzles, and games. Feel free to bring your favorite games from home.

## More From Dr. Ospina

Dr. Ospina mentioned that there are three types of drugs used to treat Parkinson’s and that a cocktail of the three types might work best. They are levodopa (L-dopa), dopamine agonists, and MAO-B inhibitors.

Parkinson’s symptoms are caused by the lack of dopamine, a neurotransmitter, in the brain. L-dopa is turned into dopamine in the brain, so it is the gold standard of drugs used to treat the disease. It is paired with carbidopa to make it more effective and to reduce or prevent nausea. Carbidopa/levodopa comes in many forms: tablet, capsule extended release (Rytary), disintegrating tablet (Parcopa), gel delivered by a pump (Duopa), and most recently, powder delivered by an inhaler (Inbrija).

Dopamine agonists act like dopamine. Examples are Mirapex, Mirapex ER (pramipexole); Requip, Requip XL (ropinirole); Neupro patch (rotigotine), and injectable Apokyn (apomorphine). The problem is that they attach to all five nerve receptors instead of just #1 and #2. Receptor #3 is the feel-good receptor. Because dopamine agonists attach to that third receptor, the drugs can be addictive. They can cause problematic compulsive and impulsive behaviors.

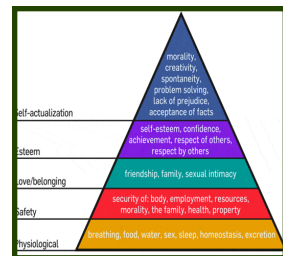
MAO-B is an enzyme that breaks down dopamine. MAO-B inhibitors slow this process helping dopamine work longer and improving the symptoms of the disease. Examples are Azilect (rasagiline); Eldepryl, Zelapar (selegiline); and Xadago (safinamide).

## Partner’s Perspective Charlene Ostlund

There’s no doubt that caregiving duties increase for us partners as Parkinson’s advances. Do you ever find yourself wishing to be on the receiving end of a little TLC? Here’s your chance!

A community event is being planned called Caregiver Day. During this event, there will be a speaker, a meal, and breakout sessions that include massages, manicures and relaxation techniques.

The event will be held at the Community Center at 780 S. Park Centre Avenue in the La Posada campus on Friday, April 26<sup>th</sup> from 2-5 pm. It is free to family caregivers, but you must register by calling Denise at 520-393-6835. Space is limited so call now.



# March 2019

Sun	Mon	Tue	Wed	Thu	Fri	Sat
					1 Exercise 9:00-9:45  Lecture 1:00	2
3	4 Exercise 9:00-9:45  SAC Club 1:00	5 Golfing 8:30	6 Exercise 9:00-9:45  Women with PD 1:00	7	8 Exercise 9:00-9:45	9
10	11 Exercise 9:00-9:45  SAC Club 1:00	12 Golfing 8:30	13 Exercise 9:00-9:45  Mandela 11:00 Brain Aerobics 1:00 FID	14 Meet & Greet 10:00	15 Exercise 9:00-9:45  Board Meeting 10:00	16
17	18 Exercise 9:00-9:45  SAC Club Cardmaking 1:00	19 Golfing 8:30	20 Exercise 9:00-9:45  Women with PD Men with PD PD Partners 1:00	21 GAP 10:00	22 Exercise 9:00-9:45	23
24/31	25 Exercise 9:00-9:45  SAC Club 1:00	26 Golfing 8:30	27 Exercise 9:00-9:45	28 Friends Night Out 5:00 Los Agaves	29 Exercise 9:00-9:45	30

## BOARD MEMBERS

### President

Tom Shoenhard

### Directors

### President-Elect

Charlene Ostlund

Joe Barton

Ann Ketterer

### Vice President

Suzanne Colley

Sue Cupell

Ken Peters

### Secretary

Bonna Cunningham

Dan Fahy

Lucinda White

### Treasurer

Marcia Heath

Bill Hanne

## Upcoming Events:

### Lecture Series



- Next lecture: **March 1, 2019**
- East Social Center (7 S. Abrego Dr.)
- 1:00p

### Meet & Greet



- Second Thursday of the month
- Old Chicago Deli
- 10:00a

### Friends Night Out



- Last Thursday of the Month
  - 5:00p Los Agaves
- Contact: Marcia Heath

### Parkinson's Exercise Class



- Monday, Wednesday, Friday
- Valley Presbyterian Church (2800 S Cmn Del Sol)
- 9:00a - 9:45a
- Led by Mia Lee Cooper

### Support Group Meetings



- First Wednesday of the month: Women with PD
- Third Wednesday: Women with PD, Men with PD, and PD Partners
- Friends in Deed (301 W. Camino Casa Verde)
- 1:00p - 2:30p

### Aquatic Tai Chi



- Cancelled until further notice
- Contact: Sue Colley

### Card Making



- 3<sup>rd</sup> Monday of the month
- Friends in Deed (301 W. Cmo Casa Verde)
- 12:30p
- Contact Charlene

### Mandala Coloring/Brain Aerobics



- 2nd Wednesday of the month
- Friends in Deed, 301 W Camino Casa Verde
- Mandalas-11:00 am/Brain aerobics-1:00 pm
- Instructor: Patricia Izzi
- Contact: Charlene Ostlund

### Golfing



- Tuesdays
- 8:30a/winter and 7:00a/summer
- Country Club of Green Valley (77 E. Paseo de Golf)
- Reduced rate!
- Contact: Joe Barton

### Gratitude, Affirmation and Prayer (GAP) Meeting



- Third Thursday of the month
- 761 S. Abrego Dr.
- 10:00a - 11:00a
- Contact: Charlene Ostlund

### Take Note!



#### SAC • Friends in Deed • Mondays • 1:00p

**March 4:** Rut-Breaker Adventures, Scattergories (a game), art project by Home Care Assistance

**March 11:** Assemble a remote-control vehicle, brain exercises

**March 18:** Card making, Rut-Breaker Adventures

**March 25:** Make & take with Janice, Rut-Breaker Adventures

**April 5:** Ice Cream Social

**April 26:** Caregiver Day event at LaPosada Center



### Additional Supporters of our Group

Country Club of Green Valley      Home Watch Care Givers  
Green Valley Recreation          Access Wisdom Care Givers  
Valley Presbyterian Church      Southern Arizona Eldercare

### Avatars

You have heard of service dogs, but have you heard of the electronic version? Read on.

Your care partner has errands to run and appointments to keep. Maybe you live alone and cannot afford in-home care 24-7. Who can? The answer may be Care.coach™.

With Care.coach™, you will see an electronic tablet showing a simulated pet. On the other end (possibly across the world) is a specially trained health advocate team that provides continuous patient support and wellness coaching.

The “pet” will remind you when it’s time to take medicine and encourage you to exercise. It can make reports to distant family members following a customized



program that you set. It will engage your care partner. It offers psychosocial support by providing compassionate conversation whenever desired—even in the middle of the night. Just as some people give their GPS voice a name and imagined personality, the simulated pet will come to feel like a real pet.

Care.coach is being used by people with certain high-risk conditions including fall-risk. Jennie Chin Hansen, past CEO of the American Geriatrics Society and past president of AARP calls it a “**game-changing innovation** for aging and geriatric care that leverages the best of both human and technological capabilities.”

Learn more online by searching care.coach.

### Sniffing Out Parkinson’s

After being diagnosed with Parkinson’s, most people realize that they had been experiencing symptoms long before diagnosis. Can an early diagnosis make a difference? Probably.

Research studies are showing that therapeutic intervention and lifestyle changes in pre-tremor Parkinson’s can slow the progression.

You never know what you might learn at our monthly group meetings. At a recent PD Partners meeting, one of the partners shared that dogs are being trained to sniff out Parkinson’s. The program is called PADs (Parkinson’s Alert Dogs) and is based on San Juan Island, Washington.

It is common knowledge that dogs have a better sense of smell than we do. They have 40 to 50 times the number of olfactory receptors than humans. Their brains are better at processing smell, but can they smell Parkinson’s? Ongoing training shows that yes, they can.

Early detection is only one reason for training dogs to sniff out Parkinson’s. PADs is working with an early stage biotech company to find the molecular basis of the disease. The researchers are using the dogs to try to identify signature molecules of PD, which could lead to a screening tool, and for researchers, lead to the cause of the disease and bring them closer to finding a cure.

To train the dogs, the program needs t-shirts that have been worn by people with Parkinson’s. If you would like to help, email [sanjuanlisa@gmail.com](mailto:sanjuanlisa@gmail.com). PADs will send a kit with a t-shirt and instructions for wearing and returning it.

Find more information at [padsforparkinsons.org](http://padsforparkinsons.org).

## Shirts—Place Your Order



If there is enough interest, we'll place another shirt order. The shirts are polo shirts in white, dark gray, or medium blue with our support group's logo. We charge \$15 each. This is not a fund raiser. The support group subsidizes the cost. The shirts are one way to publicize our existence to the community. You can place your order at any of our events this month. If you don't want to wait for the order to come in, we have a few shirts on hand:

**Women's: 2 M white, 1 L gray, 1 L white.      Men's: 1 L white**

## SAC Grand Opening





GV Support Group  
PO Box 714  
Green Valley AZ 85622

### Numbers to Record

The Green Valley Fire District provides services that may be important to you today or in the future. Keep these phone numbers handy.

Smoke alarm battery program: **520-393-7505**

Desert pest removal: **520-629-9200**

Lock box program: **520-625-9438**

Urgent care in your home/nurse practitioner: **520-428-0550** (for appointments or information). The nurse accepts Medicare and there is no copay.



### Upcoming Events:

Friday, **April 5:** Ice Cream Social

Friday, **April 26:** Caregiver Day event at Community Center