

# Parkinson's Post



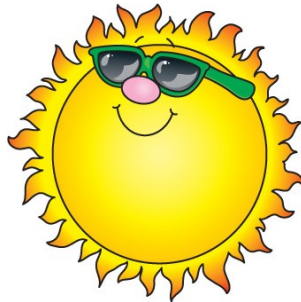
Supporting people  
with Parkinson's  
since 1991

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## From The Board

Though it's only May, it feels like the end of another year on our support group's calendar. Since the beginning of our "high" season in September, we have had six lectures (one including a shuttle ride to Dairy Queen), two talks at SAC Club, monthly support meetings, countless exercise classes, the holiday luncheon, a group discussion on end-of-life decisions, monthly breakfasts, six Friends Nights Out at local restaurants, the Grand Opening of SAC Club, weekly activities at SAC Club, golfing opportunities, an ice cream social and a float in the White Elephant parade. Whew!



Many of our activities, classes, meetings and social events will continue through the summer. *The Parkinson's Post* will be downsized to *The Parkinson's Twig*, which is distributed by email. A few printed copies will be available at exercise class and our usual events while they last.

During the next few months, your board will be planning the lecture series that will begin in September and designing a new website.

## Around the Cracker Barrel

Tune in to KGVY 1080 AM at 11:30 on May 10<sup>th</sup> for Around the Cracker Barrel. Two of our board members, Cindy White and Bill Hanne, will be interviewed about our support group. This is one more attempt to reach people with Parkinson's in the community who are not aware of our group and what it offers.

*Stay active!*  
Charlene

## Annual Meeting/Spring Luncheon

The first Friday in May is always reserved for our annual meeting and spring luncheon. This year it falls on May 3<sup>rd</sup> and will be held at East Center. Plan to be seated by noon.

The annual meeting led by President Tom Shoenhard will be brief with an introduction of board officers and directors, whose terms will begin in June, and an overview of finances.

The luncheon will be potluck. Please bring a dish to share. Tableware will be provided. We welcome Teresa Kitchens and Vanessa Leschak from Parkinson's Disease Nutrition who will be bringing a healthy dish for us to sample.



Back by popular demand is Readers Theater. Regina Ford, director, promises new, fun presentations.



## Nutritional Cooking Lesson

SAC Club will be hosting a nutritional cooking lesson at 1:00 on **May 13<sup>th</sup>**. Nutritionists from Parkinson's Disease Nutrition, a nonprofit, will be leading the class. Sign-up sheets will be available at our events since the instructors will need to know how many to expect.

Ice Cream Social

It probably shouldn't take two hours to eat a bowl of ice cream, but when you're with friends, time flies. Thank you to Sue Colley for arranging the event, to all who helped set up and clean up, to Sue Cupell and Dan Fahy for handling registration, to Ann Ketterer for managing the cookies, to Steve Brooks and Kate McCarthy for scooping ice cream and to Sue Jones for leading the senior boxing demonstration. All in all, it was a cool way to kick off Parkinson's Awareness Month!



SAC Club

Here are some of the activities from the past month or so: Janice led the make-and-take in the kitchen. Everyone took home a serving of chicken salad and another of chicken casserole. Clarissa Alvarez from Home Care Assistance led an art therapy activity directed at visual/spatial coordination. Teresa Kitchens and Vanessa Leschak of Parkinson's Disease Nutrition shared their ideas about nutrition, samples of banana walnut chocolate chip muffins and the recipe. Most weeks, Judi Bricher led Rut-Breaking Adventures. A new jigsaw puzzle is underway.

Friends Night Out

Forty-one members gathered at Arizona Family Restaurant for the April Friends Night Out. All seemed to enjoy themselves. It was a nice way to say farewell to those winter residents that will be leaving Arizona soon to head north.

Lunch with Docs™

PMD Alliance's March live online session dealt with the topic of freezing. The guest speaker was movement disorder neurologist Brent Bluett, DO of Stanford University. Only 50% of people with Parkinson's experience freezing of gait (FOG). If you are in that 50%, you may want to go online to YouTube and search for PMD Alliance. The session was recorded and should be posted by the time you read this. Dr. Bluett discussed the cause of FOG, medication options, and ways to break a freeze.

During the April session, Indu Subramanian, MD and movement disorder neurologist, addressed integrative medicine. While she covered many topics, a few things caught my attention.

- Sinemet (carbidopa/levodopa) treats bradykinesia (slow movements) and rigidity but not necessarily tremor.
• Exercise, social connections, and starting the day with gratitude (listing three things you are grateful for) are treatments in addition to prescribed drugs.
• Acupuncture may improve energy level, lessen pain, and help sleep.

Lunch with Docs is held on the fourth Wednesday of most months at noon. Go to pmdalliance.org to register.

Parkinson's Post

Editor: Dan Fahy Writers: Charlene Ostlund
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Layout: Dan Fahy Marcia Heath

Thank you to these volunteers who made this publication possible.

## Partner's Perspective

Fred Pelton

We (Marlene and I) have been attending Parkinson's support groups for more than 25 years. We have met dozens and dozens of people in the same or similar situation as ourselves. A keen observation we have come away with is every Parkinson's patient is different. And more importantly every Parkinson's patient caregiver is different.

In our support group, we are surrounded by others in the same or similar situations as us. It gives everyone an opportunity to vent about their frustrations, talk about their fears and receive support that they cannot receive **anywhere else**. In addition, we also appreciate the benefit of additional resources either from the leader or other caregivers in the group. The group is a way for us to realize we are not alone and to help us partners be the best caregivers we can be for our spouses. It allows caregivers to see how they stack up. **Am I OK?** Where are my caregiver deficits and what can I do to IMPROVE??

Though a labor of love, providing care to a spouse is demanding work, sometimes making the caregiver feel lonely and depleted. In these cases, caregiver support groups can be a powerful source of hope, support and information when times become particularly challenging.

When a loved one needs help due to dementia or other age-related diseases, our life undergoes a dramatic change. Not only will family roles change, but our everyday schedule does as well. We may also be mourning the loss of our loved one's health, relationships, and authority.

It can feel exhausting trying to juggle these new challenges. I find **our support group helps remedy many of these problems and provide support that fits my situation so that I no longer feel alone**. Those sitting with me are experiencing similar feelings and shifts in their relationships.

In fact, our support group "improves social networks and they can reduce stigma, isolation and

feelings of alienation among members."

I am not the only one who feels or has felt these things. The comfort of knowing someone understands can help me keep moving forward and adjust to the new needs of my partner. It also allows an opportunity to contribute to other caregivers,

give them words of encouragement and share hints from lessons I have learned or things I have learned from other caregivers.

Caregivers can feel guilty for being frustrated or annoyed. They have no outlet to express these feelings, so they tend to explode at the wrong time, and possibly in inappropriate ways.

Learning how to avoid this situation is VERY beneficial!!!! In our support group, we have people who are receptive to venting and frustration. They understand what we are going through and they want to help me express my feelings in a healthy situation.

When we are surrounded by others who better understand our intentions and feelings, it is easier to step back and look objectively at our situation. We are more open to accepting what the future holds for US. We are more open to adjusting our plans as things change. We also gain more depth in our understanding of services and responsibilities due to the lectures we have about medicines on the horizon, legal responsibilities, and helpful services available in the Green Valley area. The people in our support group are in different places on their caregiver journey. It is possible some have already gone through the whole trial-and-error process in finding treatments and doctors that have worked for them. They can recommend treatments and combinations you might not have heard of.

Personally, I get great satisfaction in the social networking, exercise class, dinners and breakfast at the Chicago Deli.

It's considerably easier when there are those that can help you push the rock up the hill. I love everyone in our support group, a big thanks to you all!!!!



# May 2019

Sun	Mon	Tue	Wed	Thu	Fri	Sat
			1 Exercise 9:00-9:45  Women with PD 1:00	2	3 Exercise 9:00-9:45  Potnic 12:00	4
5	6 Exercise 9:00-9:45  SAC Club 1:00	7 Golfing	8 Exercise 9:00-9:45  Mandela 11:00 Brain Aerobics 1:00 FID	9 Meet & Greet 10:00	10 Exercise 9:00-9:45	11
12	13 Exercise 9:00-9:45  SAC Club 1:00	14 Golfing	15 Exercise 9:00-9:45  Women with PD Men with PD PD Partners 1:00	16	17 Exercise 9:00-9:45  Board Meeting 10:00	18
19	20 Exercise 9:00-9:45  SAC Club 1:00	21 Golfing	22 Exercise 9:00-9:45	23 Friends Night Out 5:00 Quail Creek	24 Exercise 9:00-9:45	25
26	27 No Exercise	28 Golfing	29 Exercise 9:00-9:45	30	31 Exercise 9:00-9:45	

## 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:

### Potnic



- Friday, May 3
- Friends in Deed (301 W. Camino Casa Verde)
- 12:00p

### Meet & Greet



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

### Friends Night Out



- Last Thursday of the Month
- 5:00p Grill at Quail Creek
- 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
- **No class on Memorial Day.**

### 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

### Card Making



- 3<sup>rd</sup> Monday of the month at SAC Club
- Friends in Deed (301 W. Camino Casa Verde)
- 1:00p
- Contact: Charlene Ostlund

### Mandala Coloring/Brain Aerobics



- 2nd Wednesday of the month
- Friends in Deed (301 W Camino Casa Verde)
- Mandalas-11:00a
- Brain aerobics-1:00p
- 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)



- 10:00a - 11:00a
- Contact: Charlene Ostlund
- Location: TBD
- Contact: Charlene Ostlund

### SAC Club

- Mondays
- Friends in Deed (301 W. Camino Casa Verde)
- 1:00p - 2:45p
- Contact: Charlene Ostlund
- Games, puzzles, activities



## Additional Supporters of our Group

Country Club of Green Valley  
Green Valley Recreation  
Homewatch CareGivers  
Southern Artizona Eldercare  
Valley Presbyterian Church

### Boxing

Boxing as therapy for Parkinson’s is catching on. Several of our winter residents/visitors mentioned doing Rock Steady Boxing back home and looked for classes here.

If you are looking for exercise classes that incorporate boxing moves and coordination practice, there are a couple of nearby opportunities. At our ice cream social, exercise leader Sue Jones demonstrated aerobic exercise using boxing punches and moves. Didn’t Sue Colley, Steve Brooks, Loren Jepsen and others in the crowd look great showing off their moves? Sue leads a class called senior cardio boxing at Anamax Park in Sahuarita. The 45-minute classes are held on Tuesdays and Thursdays at 12:30 pm and cost \$5 per class. The address is 17501 S Camino De Las Quintas, which can be reached from La Canada between Duval Mine Rd. and Sahuarita Road.



Some of our members take boxing classes based on the Rock Steady model at Athlon Physical Therapy in Green Valley Village. Member Kerry Amundsen reports that the popular class grew so much that it was split into two classes. With winter residents leaving, there’s likely room for more participants.

Punch Out Parkinson’s!

### How Did I Become Treasurer?

By Marcia Heath

Bill and I first attended exercise class here as snowbirds. The class impressed us so much that within a year or two we moved here permanently thinking we needed the support.

During the first month we lived here, Bill Hanne stood up during each exercise class and asked for someone to volunteer to be treasurer. Rich Cunningham had health issues and wanted out of the job ASAP. I was reluctant to answer Bill’s plea because we were so new. But when he had asked 3 or 4 times, I went over to Bill Hanne and told him I had bookkeeping experience. And that’s all it took!! Rich showed me his treasurer’s process that week.

My experience? I worked as a property management bookkeeper, managing HUD and FmHA subsidized housing. I also programmed the firm’s bookkeeping and budgeting process using BASIC on a WANG mini computer. Later I moved on to main frame development at Boeing. I did volunteer bookkeeping during early retirement for a community clubhouse that was used and rented for various community affairs.

Volunteers don’t get paid, not because they’re worthless, but because they’re priceless.

—Sherry Anderson

### Bracelets

Don’t throw away the bracelets distributed at the ice cream social last month. There’s more than one way to publicize our support group. We hope that people in the community will spot your bracelet and ask about the support group. It doesn’t matter whether they have Parkinson’s or not. Someday they will meet someone with PD, and they’ll ask that person, “Have you heard about the support group?” Be our billboard; wear the bracelet.

## Dairy Foods and Parkinson's—Is There a Connection?

Do dairy foods cause Parkinson's disease? There was a study a couple of years ago published in *Neurology*, the journal of the American Academy of Neurology, concerning this question.

The study found no link between full-fat dairy products and an increase risk of PD. However, those people who drank skim milk or low-fat milk had a 39 percent higher risk of developing Parkinson's. Eating sherbet and frozen yogurt showed a modest increase in risk. The researchers point out that the results don't necessarily show that dairy products cause PD. Rather, they are calling it an association.



How can the difference between whole milk and skim milk be explained? When the fat is removed, the percentage of lactose (a sugar found in milk) increases. People who are lactose-intolerant are unable to break down lactose into its two subunits. When it's not

broken down, it feeds the "bad" bacteria in the gut. Remember that one thought is that Parkinson's begins in the gut.

<https://parkinsonsnewstoday.com/2017/06/29/parkinsons-disease-more-likely-among-frequent-consumers-of-low-fat-dairy-study-finds/?amp>

## PD in the News

### Felodipine

In a study, a prescription drug used to treat high blood pressure (Felodipine) reduced build-up of clumps of protein in mice with Parkinson's disease and in zebrafish with dementia. The animals also showed fewer signs of the diseases. Past research used high doses of the drug. In this test, doses like those tolerated by humans were used.

Further testing is needed in humans. If this drug proves beneficial for humans, the process of making it available to the public would be simplified since it is a re-purposed drug already approved by the FDA.

### In Memoriam

Terry Hansen (husband of Darlene Notti)

Paul Kasper (survived by his wife Debbie)

Bud Moore (survived by his wife Donna)



### Caregiver Day

Ten of our PD partners enjoyed a day of relaxation and pampering at the first annual Caregiver Day for family caregivers in the Green Valley/Sahuarita area on April 26th. Thanks go to La Posada Life Community Services and the many sponsors of the event. If you missed this year's event, don't pass it up next year!

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 Event:

**Friday, May 3: Annual Meeting/Spring Luncheon**