

Parkinson's Post



Supporting people
with Parkinson's
since 1991

September, 2019 • Inside this Issue

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From The Board

September is here!

It's time to awake from our summer siesta. There is plenty going on in the coming months to get excited about. Our lecture series begins again—the first Friday of most months through March. PMD Alliance's Renew! Retreat is in October and the Davis Phinney Foundation's Victory Summit is in December. Both will be excellent events, and we plan to provide transportation if you are concerned about driving to Tucson.

Friends' Night Out

This month's chance to eat out with other members will be on September 26th at the Firefly Restaurant in Amado. Remember that you can reach Amado using frontage roads, so you don't need to travel on I-19.

New Website

Work on our new website continues. We will also have a new email address soon. I'll keep you informed.



Legos

Did you see the article in *Brain & Life* about Lego therapy? Currently, it is being used for MS, ADHD (executive function) and autism, but will be tested for Parkinson's soon. In the studies, participants reported less fatigue and higher confidence. They also noticed improvement in fine motor skills when buttoning clothes and writing.

One participant commented that she experienced improvements in muscle control and focus. Another could lose himself in the projects and therefore cope better with pain. Yet another could feel brain fog lift, had sharper focus and was significantly more relaxed



Sound good? We would like to give it a try in SAC Club. If you have Legos to donate, please contact Charlene or email support-group@gvspd.org.

Save the Dates

Oct. 11: Renew! Retreat at DoubleTree by Hilton in Tucson (9:30 – 6:00)

Dec. 14: Victory Summit at the Tucson Convention Center (9:30 – 3:30)

Stay active!
Charlene

Here's a thought.....

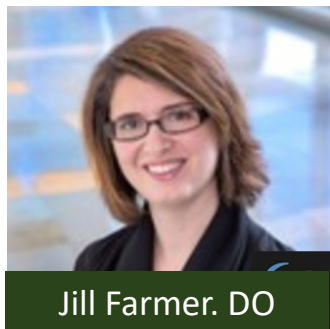
Looking for a way to help our group? A donor (You or a Friend) could donate a box of LEGO's with 790 pieces at Target for \$47.99

Pizza Potnic

The last of three summer potnics on August 2nd was a pizza party. Thanks go to Marcia Heath for ordering the pizza and to those who attended for bringing side dishes and desserts. We appreciate Friends in Deed for providing space for all of our summer potnics.

Lunch with Docs™

The topic of July's PMD Alliance's live online program was Medical Marijuana and Parkinson's presented by Jill Farmer, DO, MPH, an assistant professor of neurology and director of the Parkinson's Disease & Movement Disorder Program at Drexel Neurosciences Institute in Philadelphia, PA. Medical marijuana is legal in both states where she practices—Pennsylvania and Maryland.



Jill Farmer, DO

Dr. Farmer confirmed that there is no evidence from research trials that medical marijuana affects Parkinson's. However, she added that there is evidence from patient surveys and experiences. A 2004 survey study reported 46% experienced overall improvement and 31% reported improvement in resting tremor, 38% in rigidity, 45% in bradykinesia (slow movement) and 14% in dyskinesia.

Dr. Farmer said that medical marijuana helps nonmotor symptoms better than motor symptoms. 50% of people with PD experience pain, and Dr. Farmer does recommend medical marijuana for pain relief. Lunch Cont. above

Lunch Cont....

50% of patients experience depression or anxiety, and she has no qualms recommending it to ease anxiety (not necessarily depression). 50-90% of patients have sleep disturbances. Again, she has no qualms about recommending it for that purpose.

She said that the concern for addiction is low for medical marijuana, but it can cause memory and balance problems.

Go to YouTube and search for PMDAlliance.org to watch the entire interview.

Bike Deal

Linda Stein, alumni member, has donated a three-wheeled recumbent bike. It's a few years old, but she hasn't ridden it. We thank Linda for her generous donation.

The bike is a Mobo Triton Pro. It can accommodate riders up to 250 pounds. It has rear steering handlebars. It is geared for single speed and is recommended for flat and smooth surfaces. It has a comfortable cushioned seat.

Linda is hoping that we can raise some money with the bike, but it is even more important that it goes to someone who will use it. The Board is still considering how to make it available to one of our members. Meanwhile, you will be able to see it at the September lecture.

Parkinson's Post

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Thank you to these volunteers who made this publication possible.

Getting to Know Our Board Members

Verrrry Interesting as Artie Johnson Would Say

First of all, I am not a medical doctor nor am I schooled in the range of options associated with Parkinson's...what follows is essentially my own personal experiences which are of interest to me and might be to some of you as well.

About three months ago I began to notice that my cognitive skills were declining. My interests in group activities wasn't there anymore and that ranged from participation in the exercise sessions and Board activities to social activities. My interest in teaching adult learning classes in geopolitics and foreign affairs disappeared. My model rail-roading activities were literally "off the track." If it were not for Tres, our Standard Poodle, my physical endeavors would have consisted of going to and from the TV.

Since 2011, the VA doctors tried a number of approaches ranging from MRIs (for possible indicators) to combinations of meds, all with the same results as before. The daily med schedule was routine...carbidopa-levodopa (C/L) 25 four times a day, boosted by Azilect in the morning and an extended C/L tab at night, and a ropinirole with each C/L. Very standard approach according to what I had heard in the Wednesday discussions and at PMDAAlliance gatherings.

I was due for my annual VA session in early August. This time it would be with a new set of eyes. Using the PMDAAlliance work sheet as a guide we—a new resident, Anne, and myself—were able to go into depth on a number of points. Of concern to all three of us were the obvious dyskinesia symptoms and the decline in cognitive skills. After consultation with an *ad hoc* team of VA neurologists the recommendation was to essentially cut my meds by 50-75%. The rationale was that I might be over-medicated and what I thought were indications of the advancement of Parkinson's was not the case, the symptoms were being activated by the meds, not the reverse.

So that night and the next day I cut my meds back to 100mg of C/L four times a day—at 6:00am, 10:00am, 3:00pm and 7pm—and a 100mg C/L time-release tab at bed time.

The response was nothing short of outstanding...within 24 hours the dyskinesia symptoms were no more, I was standing straighter, and my interests in former activities were rekindled. It was virtually a return to what life had been like about a year earlier. And these changes continued to hold through the following two weeks—i.e., to this Parkinson's Post. 'Tis a mystery but I regard it as an example of the often-quoted comment that when you see one person with Parkinson's you see one person...each of us is different from each other in how Parkinson's affects us, proof of why Parkinson's is so difficult to treat.

2019-2020 Lecture Series

The theme of our upcoming lecture series is Wellness Journey with Parkinson's. Living with Parkinson's truly is a journey that lasts many years. It makes sense to live those years as well as we can.

We have six lectures planned--the first Fridays of September, October, November, January, February, and March. Some deal with the physical part of the disease and others with the emotional part. The first will be on Friday, September 6th, and addresses a topic suggested by one of our members--medical marijuana. The presenter is Bill Meeks, a medical cannabis coach. Bill is retired from a 38-year law enforcement career.

You should attend if you or your partner...

⊗ experiences chronic pain

⊗ has anxiety

⊗ is bothered by sleep disturbances including frequent trips to the bathroom during the night.

In preparation for this lecture, read the Lunch with Docs article found on page 2..

Fall Prevention Event

Each year Valley Assistance Services plans a *fall* prevention event that *falls* on or near the first day of *fall*, but this year organizers are planning a better event than ever with more speakers—some addressing topics of interest to people affected by Parkinson's. We'll share more details about the speakers when they become available.

For now, mark your calendars for September 23rd, 9:00 – 3:00. It's not necessary to stay for the entire program. Because it is on a Monday and is held at Valley Presbyterian Church, those of you who attend exercise class can check it out immediately following class.

September, 2019

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

BOARD MEMBERS

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Upcoming Events:

Lecture



- Friday, September 6
- East Social Center (7 S. Abrego Dr.)
- 1:00p
- See Related Articles on pp 6 and 3

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 Labor 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



- 3rd Monday of the month at SAC Club
- Friends in Deed (301 W. Cmo 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-11:00 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)



- Third Thursday of the month
- 10:00a - 11:00a
- Contact: Charlene Ostlund
- **New location: conference room at Posada Life Community Center**

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
Posada Life Community Services
Southern Artizona Eldercare
Valley Presbyterian Church

Needed

- Someone to video exercise class to post on YouTube
- Lego pieces that are no longer being used
- Someone to assist Ann Ketterer at the refreshment table at lectures
- Someone to assist Sue Cupell at the registration table at lectures
- Volunteer by speaking to Ann, Sue or Charlene or emailing: supportgroup@gvspd.org.

Power Chair Available

Years ago, someone donated a power chair to our support group. Since then, members in need of such a device have borrowed and used it long-term without charge. We recently replaced the battery, and once again, it is available to any member in need of it. Email supportgroup@gvspd.org or contact Marcia Heath to make arrangements.

Partners' Perspectives

We have all heard it before—respite is important for caregivers to maintain their health. As your loved one's symptoms progress, caregiving becomes more and more demanding, and respite becomes more and more important.

Consider taking advantage of our respite fund, which reimburses members up to \$600 a year when hiring professional caregivers. Contact Treasurer Marcia Heath for the form and more information or email supportgroup@gvspd.org.

Please do not use our exercise class for respite time if your loved one is high risk for falls.

Neither Instructor Mia Lee Cooper nor other members of the class are responsible for preventing your loved one from falling. In case you have never attended the class, be aware that some of the exercises are done while standing and moving. Those who are at risk of falling should stay seated during these exercises. But do they if you are not there? Remember--if your loved one falls, other members of the class may be injured, too.

Book Review by Bill Hanne

Herbs & Nutrients for Neurologic Disorders

Kurn, Sidney and Shook, Sheryl; Healing Arts Press, 2016

This is the second edition of this text. It comes at a very convenient time as more evidence that Parkinson's may have its start in the gut is coming to light. During my annual physical for many years, I would ask the MD if I should be augmenting my diet with any one of a number of "all-in-one" vitamin supplements and for the same number of years the response would be along the lines "If you want to waste your money go ahead but you really don't need them as you eat a reasonable diet and get plenty of exercise." However, with evidence now that Parkinson's may start in the gut, Kurn and Shook make a cogent argument that there are some herbs and/or nutrients that appear to be related to Parkinson's as well as other neurological disorders and may prove to be of value in terms of PD.

The sub-title to the text being "Treatment Strategies for Alzheimer's, Parkinson's, Stroke, Multiple Sclerosis, Migraine, Seizures," one should expect a detailed discussion on a number of issues related to developing and maintaining a strategy that assists in the control of PD. Kurn and Shook provide that detailed discussion with the bottom line being the importance of diet and exercise (where have we heard that before?) and the usefulness of some 23 nutrients ranging from the role of "all-in-one" vitamin supplements to cannabinoids.

To be honest, I was skeptical when Anne, my wife, suggested I read it. There was a good amount of medical language in the detailed discussions, but in terms of significance and selection of materials to be used, it was straight forward and understandable. Bottom line? My use of PD meds has not changed but the supplements suggested by Kurn and Shook have been added to my routine..."using" is "believing" in my book!

More News

Renew! Retreat

Who doesn't need a retreat now and then? This annual event in Tucson is offered by PMD Alliance. It has been popular among our members in past years, and I imagine it will be again this year. There are a few changes: the location (DoubleTree by Hilton, 445 S. Alvernon Way), one day (October 11) instead of two, no registration fee, and our support group will provide transportation if there is enough interest.

It's described as "Two concurrent programs—one life-giving retreat." Two programs because care partners, family members and adult children meet in one space while loved ones with Parkinson's meet in another room.

There will be many volunteers assisting the people with Parkinson's so that the care partners can spend time with other care partners sharing their feelings and concerns without worrying about their loved ones.

This year's agenda can be found online at pmdalliance.org. That is also where you can register. The event runs from 9:30 am to 6:00 pm. In the past, lunch has been provided.

A sign-up sheet for transportation will be available at most of our events this month. Sign up soon! The bus or van will leave and return from the Green Valley Village near Sears.

PD in the News

Estrogen improves Parkinson's disease symptoms

Brain-selective estrogen treatment improves the symptoms of Parkinson's disease in male mice, according to new research published in *JNeurosci*. These findings may help explain the sex differences in Parkinson's disease and could lead to estrogen-based treatments. www.apdaparkinson.org

Since the patients more susceptible to Parkinson's disease -- men and post-menopausal women -- have low estrogen levels, estrogen treatment might be an effective way to delay and reduce symptoms. Silke Nuber and colleagues at Harvard Medical School treated mouse models of Parkinson's disease with brain-selective estrogen and compared the motor performance of males and females before and after treatment. The female mice showed less severe symptoms at a later age, but estrogen still improved their symptoms. In male mice, the estrogen treatment reduced α -synuclein breakdown and buildup and helped with severe symptoms, suggesting that estrogen could be a viable treatment option for Parkinson's patients with low estrogen levels. They also suggest that estrogen treatment might be beneficial even after symptoms have started, which

is important because spotting neurodegenerative conditions before symptoms arise is challenging.

You may have noticed that Parkinson's disease seems to affect males and females differently. Scientists believe that estrogen protects movement neurons from PD. A research team at Harvard did a study with mice models to see if estrogen treatment would delay and reduce Parkinson's symptoms. The female mice had less severe symptoms before the treatment, but the symptoms still improved from the treatment. The treatment also improved the severe symptoms in male mice. The results suggest that estrogen treatment might help even after symptoms have started, which is important since the disease isn't diagnosed early.

Complete reference:

Female sex and brain-selective estrogen benefit α -synuclein tetramerization and the PD-like motor syndrome in 3K transgenic mice.

Rajsombath MM, Nam AY, Ericsson M, Nuber S. Neurosci. 2019 Aug 12. pii: 0313-19. doi: 10.1523/JNEUROSCI.0313-19.2019. [Epub ahead of print] PMID:31405930

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, September 6: Lecture

Monday, September 23: Fall Prevention Event