

Parkinson's Post



Supporting people
with Parkinson's
since 1991

January, 2019 • Inside this Issue

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From The Board

I think you'll agree that Green Valley is a special place. I can't think of a better place for a person affected by Parkinson's to live.

Over the years, our support group has developed partnerships with many of the healthcare agencies, residential care facilities, churches, and other non-profit organizations. Without these relationships, we could not offer the programs that we do.

Perhaps you read in Green Valley News that the **White Elephant Country Fair** once again awarded us with a grant of \$16,000. It's this annual grant that allows us to offer so many programs and make a difference to so many people. Thank you to the White Elephant, all the volunteers who work there, the people who donate their slightly used goods, and the people who shop there.

Last month, **Santa Rita Home Health Services** sponsored a lunch in memory of one of their therapist's father who had Parkinson's. To our surprise, they donated over \$700 raised by the lunch to our support group. Thank you to the workers at the home health services, Santa Rita Skilled Nursing & Rehab, Arroyo Gardens Independent and Assisted Living, and Bonita Memory Care who contributed.

Looking ahead, **Posada Life** is planning two programs for family caregivers and have invited our members to participate. We'll keep you informed.

When I contacted Sun Shuttle to invite them to come to Green Valley to help our members purchase SunGo ID's, which allow you to ride the shuttle at the lower senior or disabled rate, I learned that **GVR Foundation** is already planning such an event—not only that, but they will provide transportation to whichever rec center will be hosting. I strongly urge you to take advantage of this opportunity so that you can use the SunGo ID to come to our events.

Also, **Our Lady of the Valley Catholic Church** has invited us to participate in their health fair on January 24th. We will have a table and will be giving a talk about Parkinson's.

I hope to see you at our **SAC Club's grand opening** on Monday, January 28th, 1:00 – 2:30 at Friends in Deed. Lunch will be served. Anyone interested in planning the event should drop by Friends in Deed on Mondays during January at 1:00.

Stay active!

Charlene Ostlund

Power Chair Available

Years ago, someone donated a power chair (like a scooter) 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. Call any of our Board members (listed on page 4) to make arrangements.

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

Nonmotor Symptoms: Apathy and Anhedonia

You may be aware that apathy is a symptom of Parkinson’s disease, but what about anhedonia?

Apathy is indifference; lack of interest, enthusiasm, and concern. Anhedonia is inability to anticipate and feel pleasure. Both can be caused by insufficient dopamine and may occur together or separately.

If you receive PMDAlliance’s e-newsletter, you may have read Judy Talley’s article on the subject a few months ago. Her subtitle to the article describes these symptoms well: When Your Get Up and Go Has Got Up and Went. Does that describe you or your partner with PD?

One of the points in Judy’s article is that the person with PD doesn’t recognize that he/she is experiencing apathy and/or anhedonia. Family and friends do notice and struggle with these changes in their loved ones. Judy suggests to them adjusting expectations to what *is*, not what *was*. She also reminds care partners to honor their own dopamine by staying active and social—even if your loved one with PD chooses not to join you. It’s okay to come to SAC Club without your partner with PD!

The article also mentioned that in some cases, people with PD discover a new creative side after being diagnosed. This may be the result of starting dopamine medication. Neuroscientists now say that dopamine spurs curiosity and creative thinking.

Kudos to PMDAlliance for including educational articles in their monthly newsletters.

Late Breaking Urgent News

The FDA approved a new delivery method of levodopa on December 21. It is an inhaled levodopa powder called Inbrija and can be used to treat “off” times. Because it is inhaled, it reaches the bloodstream without going through the digestive system. The effect should be quicker and more dependable.

Parkinson’s Post Contribu-

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Thank you to these volunteers who made this publication

NEW EXERCISE CLASS GUIDELINE

and the

OPPORTUNITY FOR A BREAK EACH WEEK

As members of the Parkinson’s Support Group, we know how important it is for caregivers to have a break. Unfortunately, we need to request that caregivers whose loved one has mobility issues, (ie, falls, difficulty walking, etc.) no longer leave the person with PD unattended at exercise. This is for everyone’s safety.

We do have a possible solution for caregivers

needing a break. The new SAC Club, which officially opens in January, might just be the key to providing you a well- deserved break.

SAC Club meets every Monday at Friends in Deed from 1-3. You can bring your loved one or consider using Dial-a-Ride to bring him / her to Friends in Deed – and then back home. Call 792-9222 for the Dial-a-Ride.

SAC Club is partnering with various home health agencies to have an aide in attendance each Monday to assist members with mobility issues. Attending SAC Club could provide caregivers with a two hour break each week.

COMING IN
JANUARY

SAC CLUB

Another way to
Stay mentally **Stimulated**
Be physically **Active**
Keep socially **Connected**

January 2019

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

BOARD MEMBERS

President

Tom Shoenhard

President-Elect

Charlene Ostlund

Vice President

Suzanne Colley

Secretary

Bonna Cunningham

Treasurer

Marcia Heath

Directors

Joe Barton

Bill Hanne

Cheryl Brault

Ann Ketterer

Sue Cupell

Ken Peters

Dan Fahy

Upcoming Events:



Lecture Series

- Next lecture: **January 4, 2019**
- East Social Center (7 S. Abrego Dr.)
- 1:00p
- November Review on page 1



Meet & Greet

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



Friends Night Out

- Last Thursday of the Month
- 5:00p Grill on the Green
- Contact: Sue Colley



Parkinson's Exercise Class

- Monday, Wednesday, Friday
- Valley Presbyterian Church (2800 S Camino 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

- Tuesdays and Thursdays
- Arroyo Gardens (160 N. La Canada Dr.)
- 2:00p
- Contact: Sue Colley



Card Making

- 3rd Monday of the month
- Friends in Deed (301 W. Camino Casa Verde)
- 12:30p
- 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) Meeting

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



Take Note!

Friends in Deed • Mondays • 1:00p

- January 7: SAC Club planning meeting
- January 14: SAC Club planning meeting
- January 21: SAC Club planning meeting
- January 28: Grand Opening SAC Club



Additional Supporters of our Group

Arroyo Gardens

Green Valley Recreation

Country Club of Green Valley Valley Presbyterian Church

2019 Programs and Events



The Parkinson's Support Group of Green Valley is a 501(c)3 organization. We serve people affected by Parkinson's disease in Green Valley and other communities in southern Arizona in the Santa Cruz Valley. We do not collect dues, but we do accept donations to pay our operational expenses.

Vision: To offer those in the Parkinson's community opportunities to stay as active as possible.

Mission: We strive to raise community awareness, to offer information, and to encourage and stimulate friendships among people with Parkinson's and their families. We encourage members to stay mentally Stimulated, physically Active and socially Connected.

Motto: Give Parkinson's the SAC!

Executive Committee

Tom Shoenhard — President
Charlene Ostlund — Pres.-Elect
Suzanne Colley — Vice President
Bonna Cunningham — Secretary
Marcia Heath — Treasurer

Directors

Joe Barton
Sheryl Brault
Sue Cupell — Data Base Manager
Dan Fahy — Newsletter Editor
Bill Hanne — Past President
Ann Ketterer
Ken Peters

Our support group is run by volunteers. It is important that our volunteers are not overburdened by multiple assignments. Many hands make light work. What skills do you have that you can share? Volunteer by contacting any of our Board members listed above.

The following activities and programs are subject to change. Please read the monthly newsletter for current information.

Lectures



Our educational lectures, cosponsored by GVR, are open to the public. The speakers often use slideshows so the front seats have the best view. Come when the doors open at 12:30 or shortly thereafter and enjoy refreshments while visiting with other members. To volunteer to bring snacks, call Ann Ketterer . East Social Center (7 South Abrego Drive) 1:00 - 2:30 p, first Fridays of most months.

Luncheons

Each year we have two luncheons plus summer potlucks. The spring luncheon/annual meeting is in May. Our holiday luncheon is in December.



The summer "potnic" socials are at Friends in Deed on the first Fridays of June, July, and August.

Parkinson's Chair Exercise Class

Valley Presbyterian Church (2800 S. Cam. del Sol)
9:00 - 9:45 am on Mon., Wed. and Fri.



(Check our newsletters for exceptions.)

Mia Lee Cooper, certified exercise trainer, leads exercises that address the needs of people with PD. If the person with PD has balance issues, the partner or a caregiver should be present to assist. An exercise DVD is available for a donation. You can also participate in the classes at home by joining the exercise club Move It!™ at pmdalliance.org.

Support Group Meetings

Friends in Deed (301 W. Cam. Casa Verde)
1st Wed. of the month—Women with PD
(Sept.-May)



3rd Wed. of the month—All groups
1:00-2:30 pm (1:00-2:00 summer)

Men with PD, Women with PD, and PD Partners meet separately to socialize, share experiences and information, and offer support. The men's group is led by Clarissa Alvarez of Home Care Assistance.

Meet & Greet



2nd Thursday of the month
Old Chicago Deli
10:00 am

Contact: Sue Colley

People with PD, partners, alumni partners, and community volunteers are invited to meet for brunch and fellowship. We're more than members; we're friends.

Friends Night Out



Date, time, and location vary. Watch for announcements in the *Parkinson's Post*.

Contact: Sue Colley

We don't need a reason to socialize. We just do it!

GAP (Gratitude, Affirmation, & Prayer) Meetings



3rd Thursday of month
761 S. Abrego Dr.
10:00 am

Contact: Charlene Ostlund

People with PD, partners, and alumni partners meet together to share challenges, gratitude, and prayers. Send prayer requests to supportgroup@gvspd.org. Mark "attention: Charlene."

Aquatic Tai Chi



Arroyo Gardens (160 N. La Canada Dr.)
Tuesdays and Thursdays
2:00 pm

Contact: Sue Colley

Tai chi is credited with improving balance and relieving stress. The water is warm and offers a soft landing if one loses his/her balance.

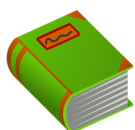
Golfing



The Country Club of Green Valley
(77 E. Paseo de Golf off of Abrego Dr.)
Tuesday mornings

Our members with PD are invited to play nine holes...on a space/cart availability basis. The fee is \$25 per month. Included are range balls, cart, chipping and putting green. Proper attire is required. If interested, contact Joe Barton.

Support Group Library



Books and pamphlets, with information about PD are available to check out. Look for our library and librarians at our monthly lectures



SAC Club is a new program and is open to all members every Monday from 1:00—3:00 pm. at Friends in Deed including people with Parkinson's, partners/ family members, and alumni partners.

The purpose of the club is to offer activities that keep our members socially connected and mentally stimulated. The activities will include games, arts & crafts, jigsaw & word puzzles and more.

One of the programs about which we are especially excited is make-and-take foods. We hope that people with PD who live alone and over-worked care partners find this helpful. Recipes will be shared.

We have partnered with four local home-care agencies (Home Care Assistance, Homewatch Caregivers, Southern Arizona Eldercare and Access Wisdom Eldercare) so that a trained caregiver is present to assist members with impaired balance.



TuLip Card Making

3rd Monday of the month
SAC Club
1:00 pm

Contact: Charlene Ostlund



People with PD, partners and alumni partners are invited to join in the fun making birthday cards for our members. No experience is needed.

Respite Care

Caregivers may need time to run errands, visit friends, get a massage, or spend time alone. To be eligible to receive reimbursement, the person with PD must be a registered member. A form (available on our website or by contacting Treasurer Marcia Heath.



Receipts for services received must be submitted to Marcia. There is a cap of \$600/year/family.

Newsletter (pullout & save)

The *Parkinson's Post* is published monthly (September to May) and is available in hardcopy or by email. The *Parkinson's Twig* (the shorter summer version) is sent by email.

PD in the News

The FDA has approved the use of focused ultrasound therapy to treat Parkinson's patients whose main symptom is tremor. This includes 10-20 percent of people with PD. The device was previously approved for essential tremor.

Focused ultrasound therapy is aimed at the same parts of the brain as deep brain stimulation (DBS), but does not involve invasive surgery. It is a permanent procedure that does not require adjustments like those needed for DBS.

Since the treatment has just been approved, there are not many places available to receive it. Sites are posted at

<https://www.fusfoundation.org/for-patients/treatment-sites>.

Clinic trials will now investigate using the therapy to treat dyskinesia, the movements caused by Parkinson's medications. Information about the clinical trials can be found at <https://www.fusfoundation.org/diseases-and-conditions/neurological/parkinsons-disease>.

In the future focused ultrasound may be used to treat other movement symptoms of Parkinson's.

Partners' Perspective

By Charlene Ostlund

Maslow's Need Hierarchy continued...

Moving up the pyramid from basic needs, next comes security needs. Everyone wants to feel safe and secure. Have you thought about how Parkinson's interferes with this need?

Psychologists say that dreams are a way of working through things that are troubling us. Consider the wild, intense, frightening dreams that many people with PD have. Is that their way of working through their fears about the disease?

Then there are the hallucinations. Some people don't find them frightening. Others do. Remember that hallucinations can be auditory. When my husband wakes me in the middle of the night saying that he hears someone in the house, it is scary for both of us. I tell him to go back to sleep and he does, but I lie awake listening. I'm now the one that gets up and checks out those things that go bump in the night. I admit that I

don't like that job but it's hard to go back to sleep unless I do so.

More symptoms of PD are paranoia and anxiety. It seems strange that my husband John and I worry about completely different things. He has no fear about things that experts warn and actions that are risky for someone with balance issues, but he can become overwhelmed with unfounded suspicions and exaggerated fears. As his partner, I try to calm those anxieties, but I'm no psychologist.

What do you and your partners with PD do to feel secure?



Green Valley AZ 85622
PO Box 714
GV Support Group

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, January 4, 2019 Lecture at East Social Center

Monday, January 28, 2019 SAC Grand Opening