

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

May 2017

Visit Our Website at:
www.faeshare.net/Parkinsons/

[Visit us on Facebook](#)

Volume 7, Issue 5

This Month's Meeting

May Meeting

Local Support Group Contacts

There were 49 attendees at our April meeting, including 2 new people. This meeting featured Allie Crandall, PharmD, from Lundbeck Pharmaceuticals Services who spoke on neurogenic orthostatic hypotension.

Barbara Harrell won the \$10 gift certificate donated to the group by the owners of the Western Sizzlin' Restaurant. Thanks to Paul and his family for being so generous.

Thanks to Ecile Shaw for delivering the prayer before lunch.

**APRIL IS
PARKINSON'S DISEASE
AWARENESS MONTH.**

Another Member Passes

I received this message from Linda Hult on Saturday, April 8: "Wanted to let you know that Evelyn O'dell passed away last evening. She was a sweet Christian lady diagnosed with Parkinson's last year. She recently had a section of colon removed and has been dealing with congestive heart failure. The surgery took a toll on her."

Dean Cook, Meeting Facilitator
Hagerstown Parkinson's Support Group
497 Hogan Drive
Martinsburg, WV 25405
Phone: 304-268-1623
Email: home2wv@yahoo.com

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the

Western Sizzlin Steakhouse
17567 York Road, Hagerstown, MD

Thursday, May 4, 2017, 11:45 AM
Featuring

Breakout Discussion Sessions

Newsletter Highlights

Tips for Making Life Easier ([Page 3](#))

Heads Up, Caregivers! ([Page 4](#))

Women with Parkinson's ([Page 5](#))

Something to Reflect on ([Page 6](#))

Detailed Event Listing ([Pages 7 & 8](#))

Future Meetings

2017

May 4, Patients & Caregivers Breakout Sessions

Jun 1, Colleen Brown, RN, BSN, Medtronic DBS

Jul 6, Dory Kennedy, Right at Home

Aug 3, Amanda Tyler, Physical Therapy and PD

Sep 7, Patients & Caregivers Breakout Sessions

Oct 5, Dr. Stephen Ryan, Physical Therapist

Nov 2, Dr. Kelly Mills, Movement Disorder Specialist, Johns' Hopkins University

Dec 7, Christmas Party & Gift Exchange



ATTEND A SUPPORT GROUP MEETING!



Local Support Group Information is on [Page 7](#).

Dean's Corner

Our First Picnic of the year is scheduled for Friday, June 16th at Snook's Park, Pavilion 4. More details to follow. For those of you who are new, there are two of these events every year, one in June and one in September. They are very well received and it gives all of us a chance to mingle, play games (especially bingo), and sample the fine food everyone brings. Please mark your calendars for the first picnic on Friday, June 16th.

Bowling – We are getting our bowling activity back on track. There were 9 bowlers and 3 spectators at the March event. This month we have reserved lanes for Friday, April 14th. We would like to get some more bowlers involved. You do not have to be a good bowler to get in the game. In fact, newbies are welcome. We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes are charging only \$2 per line including shoes.

Dean Cook
Meeting Facilitator

The Hagerstown Parkinson's Support Group

Group Facilitator:
Art Guyer

22215 Troy Lane
Hagerstown, MD 21742
240-625-2722

4Parkinsons@gmail.com

The Hagerstown Parkinson's Support Group
is supported in part by:



17567 York Road Hagerstown, MD
Stop by for lunch or dinner to support them!

Thanks to Paul Romsburg, his family, and staff of the *Western Sizzlin* for supporting our group.

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please contact the Group Facilitator, Art Guyer.

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Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3rd Monday of every month.

This month the breakfast is scheduled for **Monday, April 17 at 8:30 AM** at the **Hagerstown Family Diner**. This restaurant is located at 431 Dual Highway near the Best Western Grand Venice Hotel. Contact Art if you need information or directions.

You are encouraged to participate if possible. It gives caregivers the opportunity to seek advice in a safe environment and it allows feedback for future meetings and activities. If you need transportation, let us know and we will take care of it.

Need Transportation?



If you need transportation to our meetings or other events, please let us know.

If you no longer drive or have limited your driving and would be interested in getting a ride to one of our activities from another member, send me a note or call me and I will post a list. I am hoping there will be other members happy to help out and offer transportation.

Thanks to those good people who are already providing transportation to others on a regular basis now. You make this group special.

Ride Needed List:

Larry Pereschuk
3820 Trego Mountain Rd
Keedysville, MD (301-432-2722)

MAPS Ambassador

The Maryland Association for Parkinson Support (MAPS) has set up points of contact (Ambassadors) in each area to create visibility for MAPS in the community and to keep the Parkinson's Disease community abreast of any new activities or events planned. **Dean Cook** is our area's Ambassador.

We would like to enhance Dean's effort by getting members of our Support Group to contact businesses, offices, schools, churches, civic groups, HOAs, etc. So, **we are looking for volunteers to help distribute materials.**

Contact **Dean** for information or volunteer to help at 304-268-1623 or by email at home2wv@yahoo.com.



PICNICS COMING UP THIS SUMMER

Our First Picnic this year is scheduled for Friday, June 16th at Snook's Park. As before, it is to be held at Pavilion 4.

We plan to have another one in September.

They are well received and gives all of us a chance to mingle, play games (especially bingo), and sample the fine food everyone brings.

Please mark your calendars for the first picnic on Friday, June 16th.

More details to follow.

PD Group Bowling

We will be bowling on **April 14th**. We need to get some more bowlers involved to make it a worthwhile event. You do not have to be a good bowler to get in the game. In fact, newbies are welcome.

We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes.

Birthdays in April

Happy Birthday to members who have birthdays this month. We announced your names and sang happy birthday to you at our meeting; sorry if you missed it.



So we can celebrate your birthday at our meetings, contact Art who keeps a master schedule for the group. No years, just month and day!

In The Hospital?

If you or your spouse, or a member you know is not doing well and/or is in the hospital, please let us know. We like to visit our friends when possible. **Barb Harrell is our Sunshine Committee of One** and is responsible for sending out cards as appropriate.

Call Barb at 301-797-7845 or contact Art if you know someone in need.



Frank and Vi McConnell's Granddaughter is at Julia Manor recovering from serious injuries in an automobile accident. Please keep the family in your thoughts and prayers.

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Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

Making Your Home Safe and Accessible: Floor Coverings

Walking or wheeling on carpet is easier if the carpet pile is very short. It is easier still on wood, linoleum or ceramic floors. However, bare floors and ceramic tiles can be slippery when wet, so use caution. You may want to consider changing the floor covering or surface.

Use furniture that is sturdy and stable. Generally the best sitting chair has a relatively straight back, a firm, shallow seat and armrests. Avoid low, heavily upholstered couches and chairs, as it is often difficult to rise from them without help. Sofas or chairs should be approximately 17 inches off the ground. The seat should be no lower than knee height. Add a firm cushion or attach risers to the chair legs to increase the height of the chair. For some, a comfortable heavy rocking chair with armrests may help, as it can give you an extra boost when rising.

To get out of a chair, scoot forward to the edge of the seat, spread your feet apart and pull them back; then rock back and forth to build momentum while you push up from your chair. Get your balance before taking the first step.

This and That Thoughts on my Mind by Art Guyer: It was good to hear your voices again! For those not at the April meeting, Dean Cook arranged for the attendees to talk to Doris and I by speaker phone. It was another great idea from Dean and Carol.

We miss everyone and hope to be in attendance in the near future. Dean, Dave, and others have done an excellent job keeping the meetings going. Please take every opportunity to thank them as Doris and I do.

Take

care.....

Art

News from the Chambersburg Parkinson's Support Group: The CPSG held its first meeting in January 2017. Kathy Smith reports they had 20 people in attendance; a great start for the new group. Jan Benedick, PT, gave a presentation on LSVT/BIG for the group. The next meeting will be held on Friday, April 28th at Physical Therapy, Etc., located at 142 Farm Lane, Chambersburg, PA at 4:00 PM. The group will participate in round table discussion about staying connected to social groups and enhancing creativity. Kathy Smith, 717-377-8320, Kathy.smith@embargmail.com, Jan Benedict, 717-263-5147

New from the Friends in Frederick PD Support Group: Frederick Key's game Sunday, April 23 2017 at 2:00 pm. General admission – seniors (60 & older) \$7.00 and adults \$10.00. Please let Janet and/or Steve Silvius know how many tickets are needed. You can contact Janet or Steve at 301-831-5609.

Caregiver Support Group: The Commission on Aging has a Caregiver Support Group that meets quarterly at the Commission on Aging. It is free to attend. This newly formed group is meant to serve as a means of support for those who give of themselves as caregivers. It will give caregivers an opportunity to learn about community resources available and will give them the opportunity to connect with others who understand the caregiving journey.

This program is free and open to the public
535 E Franklin Street, Hagerstown, MD 21740
Contact: Cebrina Young at 301-790-0275 x240

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Heads Up, Caregivers: Caregiver Distress Checklist

American Cancer Association

How are YOU? Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Take a moment to answer the following questions. Then complete the self-evaluation.

During the past week or so, I have:

1. Had trouble keeping my mind on what I was doing..... Yes No
2. Felt that I couldn't leave my relative alone..... Yes No
3. Had difficulty making decisions..... Yes No
4. Felt completely overwhelmed..... Yes No
5. Felt useful and needed..... Yes No
6. Felt lonely..... Yes No
7. Been upset that my relative has changed so much from his/her former self..... Yes No
8. Felt a loss of privacy and/or personal time..... Yes No
9. Been edgy or irritable..... Yes No
10. Had sleep disturbed because of caring for my relative..... Yes No
11. Had a crying spell(s)..... Yes No
12. Felt strained between work and family responsibilities..... Yes No
13. Had back pain..... Yes No
14. Felt ill (headaches, stomach problems or common cold)..... Yes No
15. Been satisfied with the support my family has given me..... Yes No
16. Found my relative's living situation to be inconvenient or a barrier to care..... Yes No
17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____

Self-evaluation

To determine your score

1. Count up all your "Yes" responses EXCEPT do not count # 5 or 15 yet.
2. Now, look at Questions #5 and 15. If you responded "Yes" to these questions, do NOT count these with your "Yes" count. If you responded "No" to either or both questions, add these to your "Yes" count.

To interpret your response

Chances are that you are experiencing a high degree of distress:

- If you answered "Yes" to either or both questions 4 and 11; or
- If your total "Yes" score = 10 or more; or
- If your score on question 17 is 6 or higher; or
- If your score on question 18 is 6 or higher

If you are having a high degree of distress

- Consider seeing a doctor for a check-up for yourself (*Continued on next page*)

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- Look for some relief from caregiving (Talk to the patient's doctor, social worker, or care team about resources available in your community.)
- Consider joining a support group for caregivers. Online and phone support is available

If your distress level is low

It isn't unusual for caregivers to have some of these problems for a short time. But they may mean that you're at risk for higher levels of distress. When caregivers don't attend to their own needs and allow other pressures to take over, they may lose the ability to continue to care for their loved one. Part of caring for someone else is caring for yourself.

Now what?

Asking for help can be a good thing. You may need more than one kind of help to manage caring for your loved one. See a doctor if you have serious distress, or if you can't accomplish your day-to-day activities. We also encourage you to print out this checklist and talk it over with a doctor, nurse, social worker, or other professional on your loved one's care team.

Parkinson's Foundation Receives Award to Develop National Recommendations to Improve Care for Women with Parkinson's

February 28, 2017

The Parkinson's Foundation has received a \$250,000 award to develop new patient-centered recommendations to improve the health of women living with Parkinson's disease. The funding provided through a Patient-Centered Outcomes Research Institute Engagement Award will support, "Women and PD Teams to Advance Learning and Knowledge," or "Women and PD TALK" - the country's first national effort to address long-standing gender disparities in Parkinson's research and care.

"As part of our groundbreaking work to advance treatments and care for a diverse global community impacted by Parkinson's, we are proud to launch Women and PD TALK and lead the way in addressing the unique needs of women," said John L. Lehr, chief executive officer of the Parkinson's Foundation. "We are grateful to the Patient-Centered Outcomes Research Institute for its support in finding solutions that can improve women's lives."

The Parkinson's Foundation began pursuing solutions in 2013 after identifying significant gender differences in Parkinson's treatment and care, as well as the lack of any coordinated effort to address them. Historically, care has been based on research that has focused too narrowly on men or neglected to consider relevant gender differences. For example, treatment protocols have not taken into consideration the fact that women can react differently to medications or are less likely to see specialists.

"Research is beginning to prove what the medical community has long suspected: that women experience Parkinson's differently as it relates to diagnosis, symptoms, progression, treatment complications and care," said Allison Willis, M.D., M.S., co-lead of Women and PD TALK and an assistant professor of neurology, biostatistics and epidemiology in the Perelman School of Medicine at the University of Pennsylvania, a Parkinson's Foundation Center of Excellence. "We applaud the Parkinson's Foundation for putting the unique needs of women on the map with Women and PD TALK, a project that may lead to breakthroughs for women and men."

The Women and PD TALK project will charge multidisciplinary leadership teams, comprising experts in the patient, research, and health care communities, with creating recommendations to advance women's healthcare. During its two-year term, the project will establish a national network of 10 sites that will engage communities in identifying women's needs and prioritizing solutions. Regional forums, designed to educate and collect the insights of women with Parkinson's, will drive the project. Experts will utilize these insights to develop an action plan to change the landscape of Parkinson's care.

"The Parkinson's Foundation is engaging key stakeholders in Women and PD TALK to ensure that our recommendations for women's health are not only developed, but are also implemented," said Veronica Todaro, co-lead of Women and PD TALK, and vice president of national programs for the Parkinson's Disease Foundation, a division of the Parkinson's Foundation. "First, we want to understand how to improve women's lives, and then we want to make it happen."

Added Sharon Krischer, M.A., co-lead of Women and PD TALK and a person living with Parkinson's: "The time has come to understand the full picture of Parkinson's – one that takes into account the unique experiences of women. I am confident that through Women and PD TALK, by listening to the community, we can find solutions."

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Something to Reflect On

Our friend Ken McKinney lost his wife, Shirley, in February. Until last year they had facilitated the Cumberland PD Support Group. He had written this poem some time ago, but it seems so appropriate for many of us today.

On The Other Side

Ken McKinney

*Oh to speak to the ones we love,
On the other side,
To share our thoughts, our hopes, our fears,
Just why are we denied?*

*If we could only let them know,
Just what is on our mind,
To share our love, to reminisce,
Oh what a peace we would find.*

*If we could hear their voice again,
And tell them one more time,
How much we love and miss them so.
Wouldn't that be sublime?*

*But God has willed it in His plan,
To wait until that day,
When we will be together,
And with them we can stay.*

*Until that time, let's not forget,
How much there is to do.
God has given us a master plan,
And His plan is for you.*

*Heaven's portals are free from sin,
But not on this sinful side.,
So only those who trust in Christ,
Can cross over and abide.*

Thank you Ken....

If you can access the internet, here is another version of "On the Other Side" written by Dailey & Vincent. Please take the time to listen to it. https://www.youtube.com/watch?v=556E2_S52i4

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Reminders of upcoming events as of Friday, April 14, 2017

REGULAR EVENTS:

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 st Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 st Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Toby Feddis, 301-729-5569, lansgranny2007@yahoo.com Pam Dolly, 304-738-2196, pameladolly89@gmail.com
Winchester PD Support Group Monthly Meeting	2 nd Tuesday @ 11:00 AM Winchester Church of God, Winchester, VA	Cheryl Reames, 540-662-4632 winchesterparkinsons@gmail.com
Central PA PD Support Group Meeting	2 nd Wednesday @ 1:30 PM Health South Rehab Hospital, Mechanicsburg, PA	Dan Yother, 304-676-2053 oldred714@verizon.net
Hagerstown Parkinson's Support Group Caregivers' Breakfast	3 rd Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Frederick PD Support Group Monthly Meeting	3 rd Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 rd Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
Frederick County Parkinson's Early Onset or Newly Diagnosed Community Support Group	3 rd Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 bergstromdf@gmail.com
Cross Keys Parkinson's Support Group	3 rd Thursday @ 2:15 PM Cross Keys Village, New Oxford, PA	Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net
Chambersburg Parkinson's Support Group	Meets every TBD Meets at Physical Therapy Etc. 142 Franklin Farm Lane, Chambersburg, PA	Kathy Smith, 717-377-8320, Kathy.smith@embarqmail.com Jan Benedict, 717-263-5147

OTHER EVENTS:

- Monday, April 17, 2017, 8:30 – 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Wednesday, April 26, 6PM - 8:30PM Surgical Therapeutics for Parkinson's: Deep Brain Stimulation and Duopa Information Session, St. Thomas Episcopal Church, Towson, MD. Contact: GiGi Gray at 410-955-6692 or ggray8@jhmi.edu.
- Thursday, April 27, 2017, 11:30 AM – 1:00 PM Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, May 4 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Breakout Sessions, Patients and Caregivers. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Monday, May 15, 2017, 8:30 – 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Thursday, May 25, 2017, 11:30 AM – 1:00 PM Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information at 301-639-3166 or dkukor@ahcglobal.com.

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- Thursday, June 1 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Colleen Brown, RN, BSN, Clinical Specialist for Medtronic DBS. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Friday, June 16, 2017, 12 Noon -- ?, HPSG Summer Picnic, Marty Snook Park, Pavilion 4.
- Monday, June 19, 2017, 8:30 – 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Thursday, June 22, 2017 11:30 AM – 1:00 PM Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, July 6, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Dory Kennedy, Right at Home, Post Discharge Safety in the Home. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Monday, July 19, 2017, 8:30 – 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Thursday, July 27, 2017, 11:30 AM – 1:00 PM Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information at 301-639-3166 or dkukor@ahcglobal.com.

-----Cut Out and Save-----

Hagerstown Parkinson's Support Group 2017 Speaker Schedule

Date	Speaker
January 5	Patients & Caregivers Breakout Sessions
February 2	Daniel Quirk, DPT, Regional Director, FOX Rehabilitation
March 2	Jaclyn Garrish, MS, CCC/SLP, Speech-Language Pathologist, Total Rehab
April 6	Sandra Mertz, Lunbeck, Neurogenic Orthostatic Hypotension
May 4	Patients & Caregivers Breakout Sessions
June 1	Colleen Brown, RN, BSN, Clinical Specialist for Medtronic DBS
July 6	Dory Kennedy, Right at Home, Post Discharge Safety in the Home
August 3	Amanda Tyler, PT, DPT, King PT, Martinsburg, WV, Physical Therapy/PD
September 7	Patients & Caregivers Breakout Sessions
October 5	Dr. Stephen Ryan, Physical Therapist (LSVT/Big)
November 2	Dr. Kelly Mills, Movement Disorder Specialist, Johns Hopkins
December 7	Christmas Party -- No Speaker

MAKE TAX-DEDUCTIBLE DONATIONS TO THE HAGERSTOWN PARKINSON'S SUPPORT GROUP

You can make tax-deductible donations to our support group through the Maryland Association for Parkinson's Support, Inc. (MAPS), a non-profit organization that can receive charitable contributions for Parkinson's support groups, issue tax-deductible receipts to donors, and administer the funds to the designated group.

To contribute, make your check payable to MAPS. On the memo line write Hagerstown PD Support. You must write that to assure the money goes into the account that MAPS has set up for our support group.

Mail donations to: MAPS Treasurer, Box 450, Brooklandville, MD 21022