Hagerstown, MD and the Four-State Area

# Monthly Newsletter

#### December 2015

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

Volume 5, Issue 12

#### Visit us on Facebook

### **December Meeting**

#### **Local Support Group Contacts**

#### This Month's Meeting

We had 60 people at our November 5th meeting, including several new individuals.

Our speaker was Amanda Distefano, Preventive Specialist, from the Washington County Health Department. She made an excellent presentation on falls and how to prevent them, including the number of falls in Maryland that require urgent care and the cost of those falls. She highlighted the main causes of falls, where they happen, and some of the things we can do to help prevent them. Areas of concern are throw rugs on the floors, proper shoes, adequate lighting, and just plain caution - slow down, use your assistive devices, install grip bars wherever there is a need and get proper exercise!

Amanda is the Master Trainer for the free course on falls called "Stepping On" which covers this material in a much more detailed manner; it is a 7-week course, once a week, for 2 hours each. A number of our members have taken this course, including Doris and Art Guyer, Mike and Marci Saterbak, Michaela Whitaker, and others. We will circulate a new schedule for that class late December or early January because it is highly recommended.

Lu Mattern won the \$10 gift certificate to the Western Sizzlin' Restaurant donated to the group by Paul Romsburg and his family.

Thanks to Mike Saterbak for delivering our prayer.

After the meeting, Art Guyer presented Paul Romsburg Jr with a framed, group picnic photo that included the empty chair in honor of Kiem Romsburg.

Join us for our next **Parkinson Support Group Meeting** 

MARK YOUR CALENDARS

at the Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, December 3, 2015, 11:45 AM

**Breakout Discussion Sessions Christmas Gift Exchange** And Singing Christmas Songs

#### **Newsletter Highlights**

Tips for Making Life Easier (Page 3) Heads Up, Caregivers! (Page 4) Tax-Deductible Donations (Page 5) 10-Lesser Known PD Symptoms (Page 6) Detailed Event Listing (Pages 7 & 8)

#### **Future Meetings**

Dec 3, Patients & Caregivers Breakout Sessions

Jan 7, David Kukor, Accessible Home Care Feb 4, Cathy Hanson, Alzheimer's Association

Mar 3, Michelle Cines, RN, Univ. of MD Med. Ctr Apr 7, Dr. Laxman Bahroo, Georgetown UMC

May 5, Attorney Michael G. Day, Elder Care Jun 2, Patients & Caregivers Breakout Sessions

Jul 7, Candice Valencia, Trainer and Senior Yoga Aug 4, Becky Dunlop, RN, BSN, Johns Hopkins

Sep 1, Shelley Steiner, Hospice of Wash. County

Oct 6, Dr. Kelly Mills, Neurologist from JHU Nov 3, Bailey Vernon, Johns Hopkins

Dec 1 Patients & Caregivers Breakout Sessions

Berkeley County Parkinson's Support Group Debi Corbin, Facilitator, 304-886-8594 danicasgma@aol.com

Winchester Area Parkinson's Support Group Cheryl Reames, Facilitator, 540-662-4632 winchesterparkinsons@gmail.com Facebook.com/winchesterPDsupport

Cumberland Parkinson's Support Group Shirley McKinney, Facilitator, 301-729-1427 simckinney@atlanticbb.net

Friends in Frederick Parkinson's Support Group Janet Silvious, 301-831-5609. janet@fifpdsg.org or John Kraft, 301-845-6514, john@fifpdsg.org. www.fifpdsg.org

Frederick Parkinson's Disease Early Onset or Newly Diagnosed Community Support Group Deb Bergstrom, Facilitator, 301-712-5381 or dfbergstrom@comcast.net

Central PA PD Support Group - West Shore (Mechanicsburg, PA) Dan Yother, 304-676-2053. oldred714@verizon.net

Gettysburg Parkinson's Disease Support Group Paula Chaplin, 717-337-4407, pchaplin@wellspan.org

### **Attend a Support Group Meeting**



Parkinson's Events Calendar On-Line.

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.

Hagerstown, MD and the Four-State Area

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## December 2015

# Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month. In October, Dave DeHaven, Ecile Shaw, Mike Saterbak, Barbara Harrell, Art Guyer, Frank McConnell, Gloria Rith, and Carol Gaines enjoyed breakfast and discussions together.

This month, our caregivers will meet for breakfast on Monday, November 16, at the Hagerstown Family Diner at 8:30 AM. 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.

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



If you would like a couple of hours of free time and we can take your spouse for a short day trip, we will be

happy to try to work something out for you. Give Art a call or send him an email.

Respite Care is important for caregivers. You need a break every now and then. Respite care is substitute care given so the regular caregiver can take a break and get some relief from the burden of caregiving. Respite care can be for a weekend or a day or even for an hour, on a regular basis or just one time.

Sometimes respite care is given by family or friends, who want to relieve the regular caregiver of his/her burden. Or, it can be provided by paid caregivers.



# **Dancing for PD**

**Hugh McSweyn** from our Support Group is interested in conducting a Dancing for PD exercise program using a DVD he has purchased.

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If you are interested, you can contact Hugh at 717-401-0692 or by email at hugh.mcsweyn@comcast.net.

# Would you Like to be a MAPS Ambassador?

The Maryland Association for Parkinson Support (MAPS) wants to set up a point of contact in each county in the surrounding area. They need to be able to create visibility for MAPS in the community and to keep the Parkinson's Disease community abreast of any new activities or events planned. They want to get information in front of the medical community also so they will start using MAPS as a resource. This is not limited to Maryland. If you are interested in finding our more about this or you would like to volunteer for this important post, contact Ellen Talles by email at:

EllenTalles@Comcast.net

or by phone at 410-878-7164.

The first training meeting will take place on November 14, 2015 from 10:00 AM -12:30 PM in the office of JVS Rehabilitation located at 10632 Little Patuxent Parkway, Suite 129, Columbia, MD.

Here is an opportunity to step up and give something back. There is a "red lanyard" in this for those selected to participate (see "My Thoughts" on page 4.)

## **Cards**

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game. We are scheduled to play at Karen Kelly's house in Martinsburg on Thursday, November 12, 2015. We will be sharing rides to get there. **Yeah!** Road Trip to West Virginia!

### **PD Group Bowling**

Our bowling group is growing slowly but we are having fun. Come out and join us.

We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes. In November we are scheduled to bowl on the 19<sup>th</sup> at 1:00 PM.

Call **Dave DeHaven** at 301-582-2815 for more information and directions.

### **Birthdays in November**

Happy Birthday to our members who have November birthdays. We sang happy birthday to you at our meeting this month.

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.



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### Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

**Set Priorities and focus on tasks that MUST be done**. Tackle one job at a time. Break down activities into a series of smaller steps and ask others to assist you with the difficult portions of the task. Avoid working or sitting for long periods in the same position. Move around periodically.

Allow extra time to do everything from eating, drinking, and dressing to walking, talking, and writing. Recognize that everything seems to take longer when you have PD. You'll also find that simple tasks most people take for granted, like swallowing saliva, chewing food, changing facial expressions, and projecting your voice, now require conscious thought.

Plan to do activities around the times your medication gives you the most benefit. Mornings are often a better time of day to exercise and work because you are not as fatigued as in the afternoon. Even though you may bet fatigued during the day, be careful not to nap too much; otherwise, sleeping at night might be difficult. Taking a short nap after lunch can be revitalizing, but try to limit your daytime sleep to your nighttime sleep can be more restful.

Keep a list of things you want to accomplish and prioritize the tasks. Don't get side-tracked with other things unless you redo the list to reflect things of more importance. Keep a calendar/schedule of important things to remember: family birthdays, doctor appointments and treatments, and PD Support Group Activities. This will keep you organized and will help prevent missing events that can help you live a better life.

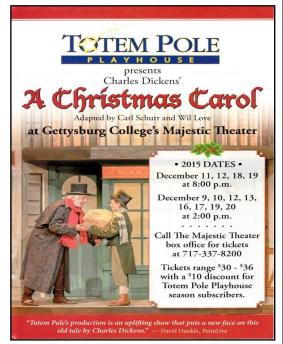
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#### **Totem Pole Playhouse**

Speaking of activities, we will be making a trip to Gettysburg on **December 16**<sup>th</sup> at 2:00 PM to see the famous Charles Dickens' play, "A Christmas Carol." As a Totem Pole Playhouse subscriber I can get top tickets for \$28 each, a \$10 discount.

Please let me know if you want to join us. We will try to arrange car pools and have dinner afterwards someplace in the Gettysburg area.





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### **Heads Up, Caregivers:**

November is <u>National Family Caregivers Month</u>. The Parkinson Disease Foundation (PDF) presented a special article to honor caregivers. Many of you help loved ones with PD with medical appointments, prescriptions and errands. Some of you face tasks such as dressing and bathing a loved one, that test your physical strength and relationships. PDF is here to support and provide resources for care partners and loved ones. This November, here are a few ideas for you or someone in your Parkinson's care network:

- **Tell Us What You Need:** Are you a caregiver or a loved one to a person with Parkinson's? We want to learn more about your journey, so we can better support it. We invite you to take <u>our 10-question survey here</u>. We'll base future programs on your feedback.
- **Get Practical Tips:** Take advantage of PDF's free educational webinar on Tuesday, November 10, <u>"Cognitive Issues: Advice for Parkinson's Care Partners,"</u> and our <u>library of online seminars designed just for care partners</u> and loved ones.
- **Find Support:** Contact our HelpLine at (800) 457-6676 or <a href="mailto:info@pdf.org">info@pdf.org</a> to get answers to your questions about PD, find caregiver resources and support groups, or to order educational materials. We are open Monday through Friday, 9:00 AM to 5:00 PM ET.

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#### This and That .... Thoughts on my Mind by Art Guyer

#### OVERALL OBECTIVE FOR 2016: GET MORE MEMBERS INVOLVED

We need to get more members involved in the day-to-day activities of our support group. As we grow larger and expand our scope, it becomes impossible for the current leader board to manage everything and keep the group going.

- Name Tag Lanyards: To be provided to members who have a high attendance record over the last year or two and/or who provide recurring and specific support to the group and the activities we undertake. They will be "awarded" in January of each year and should be seen as an indication that one is really supporting the "Support Group." Lanyards have been donated by the Guyer's.
- The Parkinson's Support Groups in Winchester and Hagerstown are hoping to set up **choirs** next year lead by the Director of New Leaf Music Therapy, Richard Lewellen. Richard is applying for a National Endowment of the Arts grant to set up choirs in those two cities. We intend to help find practice space and to help recruit members for the choir. I need someone to volunteer to help with the administrative activities of making this happen. Please contact me as soon as possible to discuss.
- Another goal I have for next year is to hold "round-table discussions" with persons with PD and/or
  caregivers at the senior facilities around the area. Perhaps a different venue each month. Anyone who
  would like to help orchestrate and/or participate in this outreach activity should email me or give me a call.

Take care..... Art

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

You can now make tax-deductible donations of any size 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 <u>memo line write Hagerstown PD Support</u>. You must write that to assure the money goes into the account that MAPS has set up for our support group.

Mail your donation to:

Treasurer MAPS P. O. Box 450 Brooklandville, MD 21022

If you have any questions or concerns about this, contact Art Guyer at 240-625-2722 or 4Parkinsons@gmail.com.



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### 10 Lesser-Known Parkinson's Disease Symptoms

The Michael J. Fox Foundation for Parkinson's Research Posted by Nancy Ryerson, August 28, 2015

Before you or a loved one received a Parkinson's disease diagnosis, you may have only been familiar with the tremor symptom. Parkinson's is different for everyone, and includes both motor and non-motor symptoms. Even after diagnosis, many are not aware of the range of symptoms the disease can involve.

Lack of awareness around certain symptoms can delay diagnosis. Even after diagnosis, it can sometimes be difficult to tell when symptoms are a part of Parkinson's disease. And if you don't know that something is a Parkinson's symptom, you may also not be aware that it can be treated.

If you're experiencing something new and you're unsure if it's related to Parkinson's, ask your doctor. A movement disorder specialist (a neurologist with additional training in Parkinson's disease) in particular will likely be well-versed in the variety of possible Parkinson's symptoms.

- 1. **Sleep disorders**. Several different sleeping problems can be part of Parkinson's disease, including insomnia, daytime sleepiness and REM behavior disorder.
- 2. **Depression and anxiety**. Depression isn't just a natural reaction to a difficult diagnosis. It's also a common symptom of the disease itself.
- 3. **Voice volume**. Parkinson's can cause slurred speech and a quieter voice. People with Parkinson's who sing may also find that their musical side is affected, too. A speech therapist, especially through the LSVT LOUD program, can help this symptom. Singing in a choir or on your own can also help strengthen your voice.
- 4. **Smell loss**. The majority of people with Parkinson's disease experience some smell loss. Though many people with smell loss do not develop Parkinson's, it seems to be the first symptom for many who do.
- Cognitive issues. Not everyone with Parkinson's experiences symptoms of cognitive impairment, but they may include memory loss, difficulty multi-tasking or problems concentrating. The symptoms can range from mild cognitive impairment to Parkinson's disease dementia (PDD).
- Orthostatic hypotension is a drop in blood pressure when changing positions, such as moving from sitting to standing that's also a non-motor symptom of Parkinson's disease. Orthostatic hypotension may cause lightheadedness and dizziness.
- 7. **Dystonia**. Both a Parkinson's disease symptom and the third-most common movement disorder, it's characterized by painful, prolonged muscle contractions.
- 8. **Facial masking**. Bradykinesia is a slowing down and/or loss of spontaneous and voluntary movement. You may move more slowly in general or swing one arm less while walking. You may also be able to show less facial expression, which is referred to as facial masking.
- 9. **Fatigue and apathy**. Many people with Parkinson's experience these frustrating symptoms. Fatigue can also result from the sleep problems associated with Parkinson's disease. If you struggle with fatigue, tackle it with these tips from our community.
- 10. Medication side effects. While not a symptom itself, many are unaware of the side effects Parkinson's disease medication can sometimes have. Use of levodopa can lead to dyskinesia, which can be described as smooth tics. Dopamine agonists have been linked with impulsive behavior. New data supports more substantial warnings for these drugs.

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## Reminders of upcoming events as of Friday, November 06, 2015

View our local Parkinson's Support Groups Calendar at: <a href="https://www.localendar.com/public/HPSG">https://www.localendar.com/public/HPSG</a>

#### **REGULAR EVENTS:**

<b>1</b>		
Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 <sup>st</sup> Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 <sup>st</sup> Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Shirley McKinney, 301-729-1427 sjmckinney@atlanticbb.net
Winchester PD Support Group Monthly Meeting	2 <sup>nd</sup> 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 <sup>nd</sup> 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 <sup>rd</sup> Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Frederick PD Support Group Monthly Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 <sup>rd</sup> 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 <sup>rd</sup> Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 dfbergstrom@comcast.net
Berkeley County Parkinson's Support Group	4 <sup>th</sup> Wednesday @ 6:30 PM Otterbein United Methodist Church, Martinsburg, WV	Debi Corbin, 304-886-8594 danicasgma@aol.com

#### **OTHER EVENTS:**

NEW! Parkinson's Disease Community Educational Series

3<sup>rd</sup> Wednesday of EVERY month (October 2015 – December 2016), 7:00 p.m. – 9:00 p.m.

St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD 21093

November 18: Management of Non-Motor Symptoms (Dr. Howard Weiss) Register

December 16: Fall Prevention (Dr. Stephen Grill) Register

Contact Bailey Vernon at 410-616-2811.

• Thursday, November 12, 2015, 1:00 PM: Parkinson's Cards. Playing at Karen Kelly's house. For directions or carpooling, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com.

• <u>Saturday, November 14, 2015, 10:00 AM – 12:30 PM: MAPS Ambassador Training</u>: The MAPS Ambassador group will be a coalition of volunteers who will help grow this new organization. Ambassadors will help gain visibility in the PD community, the medical community, and the community at large. The first training meeting will take place in the office of JVS Rehabilitation located at 10632 Little Patuxent Parkway, Suite 129, Columbia, MD.

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### December 2015

- Thursday, November 19, 2015, 12 Noon 1:00 PM Memory Café: Free lunch and meeting at Always Ron's, 29 N. Burhans Blvd, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, November 19, 2015, 1:00 4:00 PM Parkinson's Bowling: Bowl with us at the Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes.
- <u>Saturday, November 21 at 6:30 11:00 AM, Maugansville Ruritan Club Breakfast</u> (Veterans eat free, others pay \$6.00 for a great AYCE freshly made pancake, eggs, and sausage breakfast.

- Thursday, December 3, 2015 at 11:45 AM. Our regular monthly meeting will include breakout sessions and gift exchanges.
- Wednesday, December 16, 2015, at 2:00 PM: Totem Pole Playhouse Presents "A Christmas Carol" at Gettysburg College's Majestic Theater. Call Art at 240-625-2722 or email <a href="mailto:4Parkinsons@gmail.com">4Parkinsons@gmail.com</a> for information and discounted tickets.
- Thursday, December 17, 2015, 12 Noon 1:00 PM Memory Café: Free lunch and meeting at Always Ron's, 29 N. Burhans Blvd, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

Remember! Our December meeting is on the 3<sup>rd</sup> and will feature small gift exchanges. Each person should bring a wrapped present that cost about \$5.00. Put this fun event on your calendar now. We may even sing a few Christmas songs.



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

# Hagerstown Parkinson's Support Group 2016 Speaker Schedule

Date	Speaker
January 7	David Kukor, Accessible Home Care
February 4	Cathy Hanson, Alzheimer's Association
March 3	Michelle Cines, RN, University of Maryland Medical Center
April 7	Dr. Laxman Bahroo, Neurologist, Georgetown University Medical Center
May 5	Attorney Michael G. Day, Elder Care
June 2	Patients & Caregivers Breakout Sessions
July 7	Candice Valencia, Personal Trainer, Senior Yoga and Strength Training
August 4	Becky Dunlop, RN, BSN, Johns Hopkins Movement Disorder Center
September 1	Shelley Steiner, Hospice of Washington County
October 6	Dr. Kelly Mills, Neurologist, Johns Hopkins Movement Disorder Center
November 3	Bailey Vernon, Community Educator JH Movement Disorder Center
December 1	Patients & Caregivers Breakout Sessions