Hagerstown, MD and the Four-State Area

# Monthly Newsletter

**July 2017** 

Visit Our Website at: www.fareshare.net/Parkinsons/ Visit us on Facebook

Volume 7, Issue 7

**July Meeting** 

**Local Support Group Contacts** 

This Month's Meeting

There were 62 attendees at our June 1st meeting, including several new members and guests.

Our speaker was Coreen Brown, a Medtronics DBS representative who discussed the criteria, process, and benefits of having Deep Brain Stimulation surgery. She also outlined the changes made recently and some of the things coming down the road.

Dave Fleming has had his DBS surgery completed and is doing well ("a piece of cake."). He will have it turned on later this month on June 12<sup>th</sup>.

Chuck Bihun 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. She gave a special prayer for our friend, Frank McConnell, who passed away late in May.



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** 

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, July 6, 2017, 11:45 AM **Featuring** 

**Eileen McLaughlin** Owner of "Right At Home" Speaking on **Issues Faced When Hiring Caregivers** in the Home

#### **Newsletter Highlights**

Tips for Making Life Easier (Page 3) Heads Up, Caregivers! (Page 4) Expos and Frank McConnell's Obituary (Page 5) FDA Approves Xadago (Page 6) Detailed Event Listing (Pages 7 & 8)

**Future Meetings: 2017** 

#### Jun 16 Picnic at Snook's Park, Pavilion

Jul 6, Eileen McLaughlin, Right at Home Aug 3, Amanda Tyler, Physical Therapy and PD Sep 7, Patients & Caregivers Breakout Sessions

#### Sep 15 Picnic at Snook's Park, Pavilion 4

Oct 5, Dr. Stephen Ryan, Physical Therapist Nov 2, Dr. Kelly Mills, Movement Disorder Spe ialist, 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 <mark>for Friday, June 16<sup>th</sup> at Snook's Park, Pa-</mark> vilion 4 at 12 Noon. A second picnic will be held on September 15th. They are very well received and give us a chance to mingle, play games (especially bingo), and sample the fine food everyone brings. Please mark your calendars now.

**Bowling** – I have discussed bowling with the lanes and reached the following agreement: We plan to resume bowling on a regular monthly basis in July. We have worked it out with Southside Bowl that they will provide lanes for our group on the third Thursday of every month at 1:00 PM starting July 20th.

Please join us at Southside Bowl, 17325 Virginia Avenue, Hagerstown. games will continue to be \$2.00 and the bowling shoes free. You do not have to be a good bowler to get in the game. In fact, newbies are welcome.

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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## **July 2017**

### Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month.

This month the breakfast is scheduled for Monday, June 19th 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 16<sup>th</sup> at Snook's Park. As before, it is to be held at Pavilion 4 at Noon.

We plan to have another one on September 15th.

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

Please mark your calendars for the upcoming picnics.

Contact Dean for info at 304-268-1623.

### **PD Group Bowling**

We plan to resume bowling on a regular monthly basis in July. We have worked it out with Southside Bowl that they will provide lanes for our group on the third Thursday of every month at 1 PM starting July 20th. Please join us at Southside Bowl, 17325 Virginia Avenue, Hagerstown. The games will continue to be \$2.00 and the bowling shoes free.

### Birthdays in June

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 <u>your</u> 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.

<u>Leon Bromback</u> is still in rehab at the Williamsport Rehab Center. Please keep him and his family in your thoughts and prayers.

Also, keep <u>Warren Leach</u> in your prayers; he is not doing very well.

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Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

Looking Good, Feeling Better: Grooming

- Substitute a wash mitt or soft sponge for the usual washcloth. They are easier to use, lighter, and easier to wring out.
- Use Soap-on-a-Rope to prevent slips and falls that can occur in the shower. If you can't find one, make your own.
- Pour shampoo onto a sponge; then rub the sponge on your hair. It is less likely to run into your eyes.
- Keep several sets of clean undergarments in a drawer in the bathroom to change after you shower.
- Cut your toenails right after you bathe since they are less brittle and be easier to cut. Use a good clipper or short scissors.
- After eating, check your mouth for any residual food and rinse with mouthwash. Swallowing can be an issue.
- Use an electric toothbrush instead of a traditional brush if you have tremors. Or use a toothbrush with an oversized handle.
- Buy dental floss "swords" that look like the letter "C" at the end of a plastic toothpick. They can be easier than string.
- Consider buying a water pick to clean your teeth. It works well and requires less directed motion.
- Use an electric razor if you experience tremors. Test them out at stores before buying.
- Use pump-type dispensers for lotions and liquid soap; they are easier than squeezing bottles.

Upcoming subjects will cover Choosing Clothing and Shoes, and Dressing Tips, Aids, and Adaptations.

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

The good and the sad. The good is it is time for our summer picnic. The sad is that Frank and Vi McConnell will not be there to share the effort, fun and food. Let's make it a great picnic in honor of our friend Frank.

Vi..... We expect you to come back to join our activities when the time is right for you.

Please keep the family in your thoughts and prayers.....

Take care..... Art

**News from the Chambersburg Parkinson's Support Group:** The group will hold its next meeting on Friday, June 16<sup>th</sup> at 4:00 PM at *Physical Therapy, Etc.*, located at 124 Farmhouse Lane, Chambersburg, PA at 4:00 PM. Their speaker will be Ed Wenger, from the law offices of Hoskinson & Wenger. He will speak on PA Elder Law Planning. Everyone is welcome, especially those who reside in PA. The contact for this group is Kathy Smith, 717-377-8320.

**News from the Friends in Frederick PD Support Group**: They had 31 attendees at their May meeting, including several new people. Next meeting is Wednesday, June 21, 2017 at 1:00 PM - Mount Pleasant Ruritan Club. That will be there "picnic" meeting. They will not meet in July and August. You should contact Janet or Steve at 301-831-5609 for more information.

**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:

The National Parkinson Foundation book, Caring and Coping is a comprehensive guide for caregivers of people with Parkinson's at any stage. The workbook contains tips and tools to make the caring journey as productive as possible with the least amount of stress. The book focuses on your dual role as a caregiver: caring for someone with Parkinson's disease, and taking care of yourself.

The book complements <u>CareMAP</u>, NPF's online guide for people who care for someone with advanced Parkinson's. The website features 40 how-to videos and caregiver stories that offer practical and personal tips on coping with the complex problems that arise as a result of Parkinson's (from changes around the house to thinking changes to getting outside help and more).

To order a copy, visit the NPF store.

The following CHECKLIST is an example of one of the many tips and other information available in this book.



### **CHECKLIST FOR BUILDING GOOD SLEEP HABITS**

- O Establish a regular bedtime and morning awakening time that you maintain 7 days per week.
- O Design and maintain a comforting bedtime ritual.
- O Turn off the television.
- O If weaning yourself from bedtime television is difficult, try substituting relaxing music.
- O Customize your sleep environment; invest in a good mattress and pillow.
- O Keep noise and light levels low.
- O Maintain a slightly cool room temperature.
- O Keep pets from your bed.
- O Designate your bedroom for sleep and sex; it is not an all-purpose space.
- O Avoid strenuous exercise, alcohol, nicotine and caffeine within four hours of your bedtime.
- O Eliminate "checking the clock" throughout the night.
- O Limit prescription sedatives to a two-week period.



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## Members Staffing Health Expo Tables in May 2017





Frank and Vi McConnell helped set up and staff the HPSG table at the Herald-Mail Health Expo at the Elks Lodge in Hagerstown on May 6, 2017. [Three weeks later, our friend Frank McConnell passed away at the Washington Hospital Center. See his obituary below.] Kevin Noll, Carol Gaines, and Dick and Linda Hult completed the staffing that day. Dick and Linda also helped with breaking down and packing up after the show.

Carol Gaines also helped at the open house held by Farhney-Keedy on May 20th.

On May 21<sup>st</sup> Dean Cook, Joyce and Chuck Garland, and Carol Gaines staffed the table we had set up at the CARES Expo.

#### Obituary for Franklin J. "Frank" McConnell Sr.

1928 - 2017

"Franklin J. "Frank" McConnell Sr. passed away peacefully in Washington, DC on May 27, 2017. He was born in Newburgh, NY in 1928 and married Violet Simms in West Sayville, Long Island, NY on May 30, 1957. In 60 years of marriage, they have resided in Long Island, NY, Frederick, MD, New Port Richey, FL and most recently Waynesboro, PA. They raised four children, Franklin Jr., (Margaret) Holly Frey (Neil), Jennifer O'Neill (Brian), and Kimberly Koehl (Steven), and were proud to have 11 grandchildren and 15 great-grandchildren.

Frank was a veteran of World War II, and had a long career with Fairchild Industries. Per his wishes, there will not be a funeral or memorial service.

Donations can be made to: Hagerstown Parkinson's Support Group. Checks payable to: Arthur Guyer, Facilitator HPSG, 22215 Troy Lane, Hagerstown, MD. 21742."

Frank, we will miss your volunteering, your wit, and your sage advice.

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# FDA Approves Drug As Add-On Treatment For Parkinson's Disease Patients

news-medical.net March 21, 2017

The U.S. Food and Drug Administration recently approved Xadago (safinamide) tablets as an add-on treatment for patients with Parkinson's disease who are currently taking levodopa/carbidopa and experiencing "off" episodes. An "off" episode is a time when a patient's medications are not working well, causing an increase in Parkinson's symptoms, such as tremor and difficulty walking.

An estimated 50,000 Americans are diagnosed with Parkinson's disease each year, according to the National Institutes of Health, and about one million Americans have the condition. The neurological disorder typically occurs in people over age 60, though it can occur earlier, when cells in the brain that produce a chemical called dopamine become impaired or die. Dopamine helps transmit signals between the areas of the brain that produce smooth, purposeful movement – such as eating, writing, and shaving. Early symptoms of the disease are subtle and occur gradually. In some people, Parkinson's disease progresses more quickly than in others.

The efficacy of Xadago in treating Parkinson's disease was shown in a clinical trial of 645 participants who were also taking levodopa and were experiencing "off" time. Those receiving Xadago experienced more beneficial "on" time, a time when Parkinson's symptoms are reduced, without troublesome uncontrolled involuntary movement (dyskinesia), compared to those receiving a placebo. The increase in "on" time was accompanied by a reduction in "off" time and better scores on a measure of motor function assessed during "on" time than before treatment.

In another clinical trial of 549 participants, the participants adding Xadago to their levodopa treatment had more "on" time without troublesome uncontrolled involuntary movement compared to those taking a placebo, and also had better scores on a measure of motor function assessed during "on" time than before treatment.



### **Precautions**

Certain patients should not take Xadago. These include patients who have severe liver problems, or who take a medicine used to treat a cough or cold called dextromethorphan. It also should not be taken by patients who take another medicine called a monoamine oxidase inhibitor (MAOI) because it may cause a sudden severe increase in blood pressure, or by those who take an opioid drug, St. John's wort, certain antidepressants (such as serotonin-norepinephrine reuptake inhibitors, tricyclics, tetracyclics, and triazolopyridines), or cyclobenzaprine, because it may cause a life-threatening reaction called serotonin syndrome.

The most common adverse reactions observed in patients taking Xadago were uncontrolled involuntary movement, falls, nausea, and trouble sleeping or falling asleep (insomnia).

Serious, but less common, risks include the following: exacerbated high blood pressure (hypertension); serotonin syndrome when used with MAOIs, antidepressants, or opioid drugs; falling asleep during activities of daily living; hallucinations and psychotic behavior; problems with impulse control/compulsive behaviors; withdrawal-emergent hyperpyrexia (fever) and confusion; and retinal pathology.

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## Reminders of upcoming events as of Tuesday, June 06, 2017

#### **REGULAR EVENTS:**

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	Toby Feddis, 301-729-5569, lansgranny2007@yahoo.com Pam Dolly, 304-738-2196, pameladolly89@gmail.com
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 Springfield Room, Bethany Village West, 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 bergstromdf@gmail.com
Cross Keys Parkinson's Support Group	3 <sup>rd</sup> 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 2 months Meets at Physical Therapy Etc. 124 Franklin Farmhouse Lane, Chambersburg, PA	Kathy Smith, 717-377-8320, Kathy.smith@embarqmail.com

### **OTHER EVENTS:**

- 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: Eileen McLaughlin, Right at Home Owner, Issues Faced Hiring In-Home Assistance. 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.

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- Thursday, August 3, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Amanda Tyler, PT, Physical Therapy and PD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Monday, August 21, 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, August 24, 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, September 7, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Breakout Discussions. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Friday, September 15, 2017, 12 Noon --?, HPSG Summer Picnic, Marty Snook Park, Pavilion 4.
- Monday, September 18, 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, September 28, 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	Ernest Bizjak, FDA, Drug Approval Process
June 1	Colleen Brown, RN, BSN, Clinical Specialist for Medtronic DBS
July 6	Eileen McLaughlin, Owner, Right at Home, Choosing In-Home Assistance
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 <u>memo line write Hagerstown PD Support</u>. You <u>must write that</u> 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