Hagerstown, MD and the Four-State Area

Monthly Newsletter

June 2017

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

Visit us on Facebook

This Month's Meeting

There were 45 attendees at our May meet-

Our speaker was Ernest Bizjak from the

Food and Drug Administration who gave

an excellent presentation on how drugs get

from the laboratory to the consumer. He

spoke of the number of drugs that don't make it, and how long it takes the ones

that do make it. The group had a lot of

questions and he responded with solid,

Betty Martin won the \$10 gift certificate

donated to the group by the owners of the

Western Sizzlin' Restaurant. Thanks to

Thanks to Ecile Shaw for delivering the

PICNIC

Dean Cook, Meeting Facilitator

Email: home2wv@yahoo.com

497 Hogan Drive

Martinsburg, WV 25405

Phone: 304-268-1623

Hagerstown Parkinson's Support Group

What are you bringing?

Paul and his family for being so generous.

ing, including 2 new people.

understandable answers.

prayer before lunch.

June Meeting

MARK YOUR CALENDARS

Join us for our next Parkinson Support Group Meeting at the

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, June 1, 2017, 11:45 AM Featuring

Colleen Brown, RN, BSN, Clinical Specialist for Medtronic Deep Brain Stimulation

Newsletter Highlights

Tips for Making Life Easier (Page 3) Heads Up, Caregivers! (Page 4) Does PD Start in the Gut? (Page 6) Detailed Event Listing (Pages 7 & 8)

Future Meetings

2017

Jun 1, Colleen Brown, RN, BSN, Medtronic DBS Jun 16 Picnic at Snook's Park, Pavilion 4 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**

Volume 7, Issue 6

Local Support Group Contacts

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 at 12 Noon. 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.

<u>Bowling</u> – <mark>WE WILL NOT BE BOWLING</mark> IN MAY.

There were **7** bowlers and **1** spectator at April bowling.

When we resume bowling 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, May 15 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 at Noon.

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 16^{th.}

Contact Dean for info at 304-268-1623.

June 2017

PD Group Bowling

WE WILL NOT BE BOWLING IN MAY. 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 May

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.

I spoke to <u>Leon Bromback</u> late last month. In February he fell down his



cellar steps, dislocated a shoulder and broke several bones including his hip. He is in rehab at the Williamsport Rehabilitation 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: Basic Concepts

When you look good, you tend to feel better. The upcoming months will feature ways to streamline dressing so you'll have more time and energy to pursue other daily activities. Here are three basic concepts for you to keep in mind as you read the tips and suggestions on this topic:

1. Dressing will be easier when your medications are working, so plan to dress during your "on" time.

2. Allow enough time so you don't feel rushed. Gathering all your clothing items together before you start to dress will save steps and time. You may even find it helpful to lay your clothe3s out the night before. Then if you plan to wear something that needs to be hooked at the back, for example, you can ask for help before family members go off for the

3. If your balance is unsteady, sit on the bed or in a sturdy chair with armrests when you dress. You may also want to sit when you do your hair, shave, or apply makeup. Look into a "Butler's Chair" perhaps. Mine has a place on the back to hang clothes for the next day and a drawer under the seat where I keep underwear, socks, and handkerchiefs.



June 2017

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

This and That Thoughts on my Mind by Art Guyer:

My thoughts are with you all. It was wonderful seeing so many of you again at the meeting this month. There were tears a plenty. Now lets try to get the attendance back up to where it was last year. Bring a friend.

Take care Art

day.

News from the Chambersburg Parkinson's Support Group: The group will hold its next meeting on Friday, June 16th at 4:00 PM at *Physical Therapy, Etc.*, located at 124 Farmhouse Lane, Chambersburg, PA at 4:00 PM. Contact for this group is Kathy Smith, 717-377-8320.

News from the Friends in Frederick PD Support Group: Next meeting is Wednesday, May 17, 2017 at 1:00 PM - Mount Pleasant Ruritan Club. Guest speaker will be from the *Brain and Balance Center*. You can 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:

Getting Organized

National Parkinson Foundation

Caring for someone with Parkinson's disease (PD) means lots of medical records, medical and family contact lists, financial documents and other information that needs to be kept organized and handy. To avoid getting overwhelmed, below are some tips on what information to gather and how to keep it all organized.

It's not all about the person with Parkinson's. Make sure to keep your records organized, too!

Create a binder with the following main document categories: *Medical, Family, Insurance and Property, and Finance*. Even though a lot of information can be managed online, it can be good to have a physical copy of everything in one place. Wherever you choose to maintain the records, make sure that a close family member or friend knows where they are in case they are needed.

Medical information

It is particularly important to keep medical information up-to-date so first responders can access it in case of an emergency. Keep these records (for both you and the person with Parkinson's) updated and in a location where they can be easily found. Some people keep it near their medications, as emergency personnel will often seek these out if called to your home.

Information to include:

- Date information was last updated
- Name, address, phone number and date of birth
- Current medications (both prescription and over-the-counter), with prescribing physician, purpose, dosage and frequency (use the Medications and Schedule worksheet)
- Primary and specialty care physicians and contact information (use the My Contacts worksheet)
- Allergies
- Medical conditions
- Surgeries (and year)
- Blood type
- Advance directives
- Names and phone numbers of two emergency contacts (use the My Contacts worksheet)

Family documents

List contact information for family members, close neighbors, relatives or co-workers who need to be notified in case of emergency. Include important in-house locations of items such as an extra house key, electrical breaker box, water cut-off, thermostat and alarm system. Just asking, "Where is the fire extinguisher?" may bring important things to your attention, such as no working fire alarms in place!

List names and contact information for family service providers, such as the following:

- Attorney
- Accountant
- Banker
- Broker or investment counselor
- Clergy
- Doctors, dentists, veterinarian
- Home and appliance service people
- Insurance agents
- Pharmacy
- Utility company

(Continued on Next Page)

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(Continued) Also include in this section:

- Copies of (updated) wills and trusts
- Birth certificates
- Social security cards
- Military discharge papers
- Marriage license, divorce decree
- Passports
- Disability verification
- Advanced directives to physicians
- Durable power of attorney
- Written instructions regarding funerals, burial or cremation, etc.

Insurance and property documents

Write down the location of original insurance policies, deeds and mortgage papers in your home, if they are not kept in a bank safe deposit box. If maintained at home, keep these documents in a fireproof safe.

Insurance information checklist:

- Life (including any accidental death policy in place at work, credit union, etc.)
- Health
- Homeowner
- Automobiles, boats, recreational vehicles
- Disability
- Long-term care
- Professional liability coverage, if applicable

Property information checklist:

- List and locations of mortgage papers on any real estate property
- Titles and license receipts for automobiles, boats, recreational vehicles
- Receipts for any major property improvements
- Receipts for any major vehicle repair/maintenance expenses

Optional business documents: If you own a business, you might want to include the following information:

- Name and type of business
- Location of keys
- Structure for tax purposes (sole proprietorship, partnership, corporation, etc.)
- Contact information for partners and key associates
- Contact information for accountants, attorneys, bank officer
- Business account numbers and name of bank officer knowledgeable about account(s)
- Copies of documents such as tax records, employee and vendor contracts

Financial documents

Financial information is particularly sensitive, so it might be advisable to keep these records separately from the medical, family and insurance and property documentation. However, it is still important to regularly update information regarding the following:

- Bank and credit union accounts and persons authorized to sign transactions
- Safe deposit boxes
- Credit union accounts
- Location of checkbooks and account records
- Credit and debit cards, including location of payment records for the previous year
- Investment accounts

Keep account numbers and passwords in a safe location that you share with a trusted family member or friend.

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Study Provides Preliminary Evidence PD May Start In the Gut

News-Medical.Net, April 27, 2017

Parkinson's disease may start in the gut and spread to the brain via the vagus nerve, according to a study published in the April 26, 2017, online issue of Neurology, the medical journal of the American Academy of Neurology. The vagus nerve extends from the brainstem to the abdomen and controls unconscious body processes like heart rate and food digestion.

The preliminary study examined people who had resection surgery, removing the main trunk or branches of the vagus nerve. The surgery, called vagotomy, is used for people with ulcers. Researchers used national registers in Sweden to compare 9,430 people who had a vagotomy over a 40-year period to 377,200 people from the general population. During that time, 101 people who had a vagotomy developed Parkinson's disease, or 1.07 percent, compared to 4,829 people in the control group, or 1.28 percent. This difference was not significant.

But when researchers analyzed the results for the two different types of vagotomy surgery, they found that people who had a truncal vagotomy at least five years earlier were less likely to develop Parkinson's disease than those who had not had the surgery and had been followed for at least five years. In a truncal vagotomy, the nerve trunk is fully resected. In a selective vagotomy, only some branches of the nerve are resected.

A total of 19 people who had truncal vagotomy at least five years earlier developed the disease, or 0.78 percent, compared to 3,932 people who had no surgery and had been followed for at least five years, at 1.15 percent. By contrast, 60 people who had selective vagotomy five years earlier developed Parkinson's disease, or 1.08 percent. After adjusting for factors such as chronic obstructive pulmonary disease, diabetes, arthritis and other conditions, researchers found that people who had a truncal vagotomy at least five years before were 40 percent less likely to develop Parkinson's disease than those who had not had the surgery and had been followed for at least five years.

"These results provide preliminary evidence that Parkinson's disease may start in the gut," said study author Bojing Liu, MSc, of the Karolinska Institute in Stockholm, Sweden. "Other evidence for this hypothesis is that people with Parkinson's disease often have gastrointestinal problems such as constipation that can start decades before they develop the disease. In addition, other studies have shown that people who will later develop Parkinson's disease have a protein believed to play a key role in Parkinson's disease in their gut."

The theory is that these proteins can fold in the wrong way and spread that mistake from cell to cell.

"Much more research is needed to test this theory and to help us understand the role this may play in the development of Parkinson's," Liu said. Additionally, since Parkinson's is a syndrome, there may be multiple causes and pathways.

Even though the study was large, Liu said one limitation was small numbers in certain subgroups. Also, the researchers could not control for all potential factors that could affect the risk of Parkinson's disease, such as smoking, coffee drinking or genetics.



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Reminders of upcoming events as of Saturday, May 06, 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 2 months Meets at Physical Therapy Etc. 124 Franklin Farmhouse Lane, Chambersburg, PA	Kathy Smith, 717-377-8320, Kathy.smith@embarqmail.com

OTHER EVENTS:

- <u>Monday, May 15, 2017, 8:30 10:00 AM, Caregivers' Breakfast</u>: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Saturday, May 20, 2017, 2</u>:00 4:00 PM, Farhney-Keedy Open House. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Sunday, May 21, 2017, 12 Noon –</u> 5:00 PM, CARES Expo, Daikon at Robinwood Assisted Living. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Thursday, May 25, 2017, 11:30 AM 1:00 PM Memory Café</u>: 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.
- <u>Thursday, June 1 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting:</u> <u>Colleen Brown, RN, BSN, Clinical Specialist for Medtronic DBS.</u> Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- Friday, June 16, 2017, 12 Noon -- ?, HPSG Summer Picnic, Marty Snook Park, Pavilion 4.

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- <u>Monday, June 19, 2017, 8:30 10:00 AM, Caregivers' Breakfast</u>: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Thursday, June 22, 2017, 11:30 AM 1:00 PM Memory Café</u>: 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.
- <u>Thursday, July 6, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Dory Kennedy, Right at Home, Post Dis-</u> <u>charge Safety in the Home</u>. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> 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 <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Thursday, July 27, 2017, 11:30 AM 1:00 PM Memory Café</u>: 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.
- <u>Thursday, August 3, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting</u>: Amanda Tyler, PT, Physical Therapy and PD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> 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 <u>4Parkinsons@gmail.com</u> or 240-625-2722.

-----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	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 <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