

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

October 2016

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

Volume 6, Issue 10

[Visit us on Facebook](#)

This Month's Meeting

October Meeting

Local Support Group Contacts

There were 60 people at our August meeting, including 8 new members. It was another great turnout.

Our speakers were Shelly J. Steiner and Marie Hager from the Hospice of Washington County. They discussed the LifeCare of Washington County Program, a unique practice that provides support for patients struggling with symptoms and pain affecting the patient's quality of life due to serious illness or a chronic disease. Palliative care can make a patient more comfortable right now.

They did an excellent job describing the program, how it related to Hospice, how to utilize the care, and how it is funded.

Anyone interested in learning more about this important program can call 301-671-2171.

Barbara Harrell won the \$10 gift certificate donated to the group by the owners of the Western Sizzlin' Restaurant.

Thanks goes out to **Ecile Shaw** for delivering the prayer before lunch. And thanks to **Dave DeHaven** and all the others who help make the meeting a success. Good job all.

Doris and Art Guyer attended this meeting, having missed the two previous ones due to Doris' accident and rehab effort. They were welcomed back warmly and thanked everyone for their good wishes and prayers.

Please keep **Connie Hipp** and family in your prayers as she continues her recovery.

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the
Western Sizzlin Steakhouse
17567 York Road, Hagerstown, MD

Thursday, October 6, 2016, 11:45 AM

**Our speaker will be
Dr. Kelly Mills, a Movement Disorder Specialist Neurologist from
Johns Hopkins in Baltimore.**

Newsletter Highlights

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

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

Duopa Primer ([Page 5](#))

Excessive Behaviors ([Page 6](#))

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

Future Meetings

Sep 16, Picnic in the Park (See Page 2)

Oct 6, Dr. Kelly Mills, Neurologist from JHU

Nov 3, Heini Calara RN, Abbvie

Pharmaceuticals, with a Duopa Patient

Dec 1, Patients & Caregivers Breakout Sessions

December Meeting will be Christmas Party Too

2017

Jan 5, Patients & Caregivers Breakout Sessions

Feb 2, Daniel Quirk, DPT, Fox Rehabilitation

Mar 2, Jaclyn Garrish, Speech-Language Path.

Apr 6, Sandra Mertz, Neuro. Ortho. Hypotension

May 4, Patients & Caregivers Breakout Sessions

Winchester Area Parkinson's Support Group
Cheryl Reames, Facilitator, 540-662-4632
winchesterparkinsons@gmail.com
[Facebook.com/winchesterPDsupport](https://www.facebook.com/winchesterPDsupport)

Cumberland Parkinson's Support Group
Toby Feddis, 301-729-5569,
lansgranny2007@yahoo.com
Pam Dolly, 304-738-2196,
pameladolly89@gmail.com

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,
bergstromdf@gmail.com

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

Cross Keys Parkinson's Support Group
(New Oxford, PA)
Daune Wynn, 717-495-5671
wynn574@crosskeysvillage.net

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.

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Caregiver's Breakfast

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

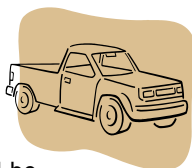
This month the breakfast is scheduled for **Monday, September 19th at 8:30 AM** at the **Hagerstown Family Diner**. This restaurant is located at 431 Dual Highway near the Best Western Grand Venice Hotel. Contact Art if you need information or directions.

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?

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.

ATTENTION:

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.

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.

Picnic Time Again

Where: Martin L. Snook Memorial Park, Pavilion #4, Hagerstown, MD

Dates: **Friday, September 16, 2016**
Time: 12 Noon

RSVP REQUESTED

Bring a covered dish or dessert and there will be fried chicken. We will provide drinks, eating utensils, and paper plates, cups, and napkins.

The cost of the chicken and the fee for rental of the pavilion will be prorated to those attending. Historically, this has been about \$4-\$5 a person.

There will also be free bingo for all, as usual! Everyone should bring one or more wrapped, inexpensive "prizes" for bingo winners. Prizes can be something you want to get rid of or you can pick up some items from a "dollar store."

Pavilion #4 is at the end of the park road when you enter from Halfway Boulevard. Contact Art Guyer or Dave DeHaven if you need information or directions.

Cards

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game. **We are not scheduled to play cards this month.**

PD Group Bowling

Our bowling group is growing slowly and we are having fun. We had a good turnout in June. Come out and join us. 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. We are scheduled to bowl on **Friday, September 23rd at 1:00 PM**. The change is due to league startup.

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

Birthdays in September

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



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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: Railings and Grab Bars

Install hand railings on both sides of a stairway. Even only one or two steps can be treacherous. Consider installing a railing along a long hallway in your home to give support as needed.

Place "U-Shaped" handles at strategic doorway locations to help navigate through the doorway more easily. Depending on your balance issues, you may want grab bars near drawers and cabinets. Install grab bars wherever you need to hold onto something sturdy when transferring from one place to another, such as to the toilet or tub. Place them where they will give the most help.

When installing railings or grab bars, they must be securely anchored to wall studs. Get professional advice or assistance if you can't do the installation yourself.

Installing a floor-to-ceiling pole by the bed, toilet, living room chair, or dining room table can be useful in steadying or balancing and to help get to a standing position. These are light-weight poles held in place by controlled tension and require no special tools or permanent installation.

This and That Thoughts on my Mind by Art Guyer:

As our group grows and as some members no longer feel safe driving, there is an increasing need to provide transportation to a few members. As I have mentioned before, I want to create a list of individuals who want to attend our activities but need help getting there. Two individuals have asked for transportation help so far and I know there are a few others out there who rely on others for rides. Here are the two names I have so far; please contact them directly if you are willing to provide transportation:

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

Glenda Austin
1625 Woodlands Run
Hagerstown MD
301-791-1361
glamealey210@verizon.net



I understand that Ragan and Ecile Shaw will be providing transportation for Glenda Austin!

Take care..... Art

AN EARLY ALERT!

Last year we began a program to recognize special individuals in the Hagerstown Parkinson's Support Group for their outstanding contributions, dedication and assistance to our support group family. Our intent was to honor two members each year who meet those criteria. To make it a complete surprise last year Doris and I made the determinations ourselves, but we promised we would look for input from the group for awards made in the following years. Last year's awards went to Dave DeHaven and Connie Hipp.

So start thinking about who you might like to nominate for the awards this year. We have so many good candidates it will be hard to narrow it down to just two, as it was last year. I will be providing a form and further guidance and information over the next few months. We will want to make these awards at our January 2017 meeting.

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Heads Up, Caregivers: ADVICE FOR CAREGIVERS

Partners in Parkinsons

Whether you live with a Parkinson's patient, or help a family member or friend with Parkinson's often, you likely face some of the issues associated with "caregivers."

As a caregiver, your state of mind and overall health can impact your ability to provide the care your loved one needs, at the level you want to give. It's important to remember that you need to take care of yourself when taking care of someone with Parkinson's disease, especially as they become more dependent on you.

Caring for someone who has Parkinson's can bring with it a range of emotions. You may feel particularly loved and appreciated and may have a sense of pride in being able to provide care and support. On the other hand, there may be moments when you feel overwhelmed, sad or angry at the situation, or even frustrated with the person you care for. First, you should understand that these feelings are normal and nothing to be ashamed of. You are providing care, but you're also part of a relationship. Like all relationships, this one will continue to require patience and understanding.

Caregiving can feel like a 24/7 job, and it is important to stay in touch with yourself by pursuing your own interests and keeping active. Asking family and friends for help, or finding professional in-home care, can give you time to yourself to reenergize and refresh. It can also give you and the person you care for new things to talk about and may help to reduce feelings of isolation.

There are also practical things that you can do to help your loved one get the best care.

- **Stay organized** – Keep a record of your loved one's medications, doctor visits and symptoms to make appointments more beneficial and efficient.
- **Know the limitations of your coverage** – Educate yourself on your insurers' practices for reimbursement of medical care so you can plan accordingly.
- **Do your homework** – Gather information on Parkinson's disease and treatment and care options so you can serve as your loved one's advocate and help plan for the future.
- **Observe your loved one's disease** – Share with your loved one's doctor if you observe symptoms such as motor function changes, mood/anxiety concerns or speech issues that your loved one may not notice or may not mention
- **Discuss important plans and decisions for the future**– Talk about wills, advanced directives and other life issues.



Getting accurate information through open and honest conversation can make a difference in your loved one's care. So it's important to focus on communication between you, your loved one and their treatment team.

And please remember, your local support group can be a wonderful resource for education, transportation, respite, advice, and just good old moral support and friendship.

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AbbVie Announces U.S. FDA Approval of DUOPA™ (carbidopa and levodopa) Enteral Suspension for the Treatment of Motor Fluctuations in Patients with Advanced Parkinson's Disease

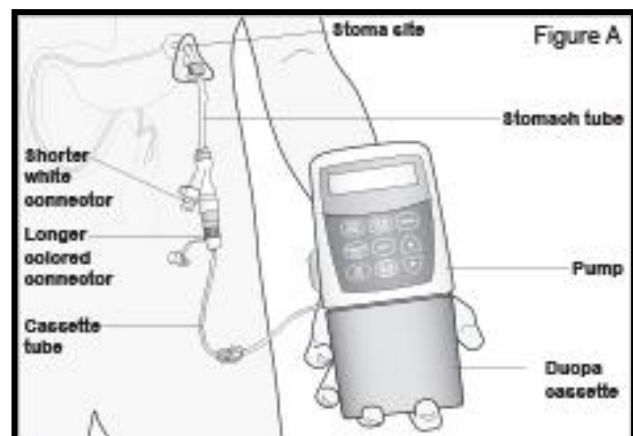
In November we are having a speaker and patient from Abbvie make a presentation on one of the latest FDA approved Parkinson's Disease treatments. This article will give you some heads-up information on the subject and perhaps let you form some questions for the speakers.

AbbVie's DUOPA™ (carbidopa and levodopa) enteral suspension is for the treatment of motor fluctuations for people with advanced Parkinson's disease. DUOPA is administered using a small, portable infusion pump that delivers carbidopa and levodopa directly into the small intestine for 16 continuous hours via a procedurally-placed tube.

Duopa suspension is an antidyskinetic combination. Levodopa is transformed by the body and the brain into a substance that helps to decrease tremors and other symptoms of Parkinson disease. Carbidopa helps levodopa to reach the brain.

Some medical conditions may interact with Duopa suspension. Consult your doctor if you have any medical conditions, especially allergies, heart issues, and any other serious illnesses. Some medicines may interact with Duopa suspension, such as MAOIs, certain antidepressants, and some blood pressure medicines. This is not be a complete list of all interactions that may occur. Ask your health care provider if Duopa suspension may interact with other medicines that you take.

In the advanced stages of Parkinson's disease, patients may begin to experience "off" time, or periods of poor mobility, slowness and stiffness. Additionally, in Parkinson's disease patients, the spontaneous emptying of the stomach becomes delayed and unpredictable, which can affect the timing of when orally administered medicines leave the stomach and are absorbed in the small intestine. DUOPA provides patients with the same active ingredients as orally-administered carbidopa and levodopa immediate release, but is delivered in a suspension that goes directly into the small intestine via a tube (See Figure A) placed by a percutaneous endoscopic gastrostomy procedure with jejunal extension (PEG-J). This type of administration is intended to bypass the stomach.



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Why Do I Keep Doing This?

Article written by Jackie Hunt Christensen.

Some people who have Parkinson's disease will develop compulsive behaviors while receiving dopamine-replacement therapy. Known as impulse control disorders (ICDs), these behaviors may include compulsive gambling or shopping, hoarding or hyper sexuality. An impulse control disorder (ICD) is the inability to stop doing something that is harmful, or could become harmful, to yourself or others. Performing the harmful activity is believed to relieve anxiety and tension.

Scientists have known for a long time that dopamine-related drugs for Parkinson's could be linked to ICDs in some patients. However, it was not until 2004 that people living with Parkinson's began to learn that ICDs could be a rare side effect of dopamine agonists. By 2007, researchers at the National Institute for Neurological Diseases and Stroke (NINDS) were reporting that these behaviors could affect up to 14 percent of Parkinson's patients on dopamine agonists. Today, that number is thought to be even higher.

Currently, most medications for Parkinson's---including amantadine, levodopa, pramipexole, pergolide, ropinerole, selegiline and others, as well as surgical treatments such as pallidotomy and deep brain stimulation---have been linked to impulse control disorders in scientific studies. The ICDs found in people living with Parkinson's include compulsive gambling, compulsive shopping, hypersexuality, hoarding, and compulsive computer usage.

Compulsive gambling can include bingo, paper or electronic pulltabs, lottery tickets and "scratch-offs," casinos, Fantasy Football or competitive bets between friends. It can be much larger and dangerous also.

Compulsive shopping involves buying things you do not need, and sometimes in large quantities.

Hypersexuality can include demanding sex and becoming abusive if your demand is denied; talking about sex and your desire for sex at inappropriate times; cross-dressing; and having affairs.

Compulsive computer use has yet to be officially characterized as an impulse control disorder. However, there are hundreds of anecdotal reports from people with Parkinson's and their caregivers about the number of hours spent using a computer, typically "surfing" the Internet.

If you suspect you have an ICD, here is what you should do:

- Keep a drug diary and record changes in your mood or behavior, as well as physical responses.
- If you find yourself starting to engage in any of the behaviors listed above or doing things that you feel guilty doing, talk to someone about it! A support group member, your doctor or someone from your place of worship are potential resources.
- Let your family know what is happening, because the problem affects them, too. Realize that ICDs could be a significant stressor on a marriage.

What can be done to treat medication-induced impulse control disorders? If the medications in question are dopamine agonists or monoamine oxidase (MAO) inhibitors (for example, Pramipaxole, Ropinirole, Rasagiline, Rotigotine patch), the doctor may have you reduce the dosage of the medication, taper off and stop the drug completely, switch to a different medication.

If the likely cause of the ICDs seems to be related to levodopa or surgery, the physician may:

- have you see a psychiatrist to evaluate whether the behavior is Parkinson's-related or a separate mental health issue.
- refer you to a psychotherapist who will help you to identify any cues that trigger the urge to gamble or shop, and then identify actions you might take to deal with those urges.
- connect you with a social worker or social service agency that can refer you to support groups that deal with impulse control disorders.
- refer you to a psychiatrist who may prescribe naltrexone, a drug that is used to treat alcohol and narcotic abuse. It is generally considered when nothing else has worked.

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Reminders of upcoming events as of Saturday, September 03, 2016

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

OTHER EVENTS:

- Friday, September 16, 2016, Noon – 3:00 PM, HPSG Picnic. Bring a dish and a Bingo Prize. For directions or information, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.
- Monday, September 19, 2016, 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, September 21, 2016, 7:00 – 9:00 PM, Johns Hopkins PD Community Education Series
Subject: Legal Planning (Jason Frank, CELA)
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795 Email ggray8@jhmi.edu. Register.
- Thursday, September 22, 2016, Noon – 1:00 PM Memory Café: Free lunch and meeting at Ledo Pizza Restaurant located at 1423 Dual Highway, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dku-kor@ahcglobal.com.
- Friday, September 23, 2016, 1:00 PM – 4:00 PM, HPSG Bowling. At Southside Bowls, Virginia Avenue; for directions or information, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com.

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- Thursday, October 6, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker is Dr. Kelly Mills, Johns Hopkins Parkinson's and Movement Disorder Center, Baltimore, MD.
- Saturday, October 15, 2016, 7:00 AM, Pacing 4 Parkinson's, M&T Bank Ravens Stadium, Baltimore, MD. Contact: Phone 410-955-8795; Email rdunlop@jhmi.edu. www.pacing4parkinsons.org.
- Monday, October 17, 2016, 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, October 19, 2016, 7:00 – 9:00 PM, Johns Hopkins PD Community Education Series
Subject: Driving (Jan Crye, OTR/L, CDRS)
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795 Email ggray8@jhmi.edu. [Register](#).
- Thursday, October 27, 2016, Noon – 1:00 PM Memory Café: Free lunch and meeting at Ledo Pizza Restaurant located at 1423 Dual Highway, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

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- Thursday, November 3, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Heinji Calara RN, Abbvie Pharmaceuticals, with a Duopa Patient.
- Wednesday, November 9, 2016, 6:00 PM – 8:30 PM, Johns Hopkins PD Surgical Treatment: DBS and Duopa
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795. Email ggray8@jhmi.edu.
- Wednesday, November 16, 2016, 7:00 – 9:00 PM, Johns Hopkins PD Community Education Series
Subject: Memory & Cognition (Dr. Liana Rosenthal, MD)
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795 Email ggray8@jhmi.edu. [Register](#)
- Friday, November 18, 2016, 9:00 AM – 12 Noon, Johns Hopkins PD Newly Diagnosed Forum
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795 Email ggray8@jhmi.edu.
- Monday, November 21, 2016, 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.

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