Hagerstown, MD and the Four-State Area

Monthly Newsletter

February 2020

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

Volume 10, Issue 2

This Month's Meeting

February Meeting

I can't tell you how much I appreciate **Carol Gaines** facilitating the January meeting. From what I have been told, she did a great job. Mike Saterbak gets a turn next month! Make sure you attend this one to support our board members and hear a great speaker.

There were **38** people at our January 2nd meeting, including 5 newcomers. **Amanda Distefano**, from the Washington County Commission on Aging, was our speaker. She provided a lot of useful information for the group. By the way, Dean Cook attended also, which made everyone happy.

Linda Bryant, one of our new attendees, won the \$10 gift certificate for the Western Sizzlin' Restaurant. The gift certificates are donated to the group by the owners of the Western Sizzlin' Restaurant. Thanks to Paul and his family for being so generous in their support of the group.

Thank you, Mike Saterbak for delivering our prayer. Thanks to Judy and Sam Fiery and Carolyn and Holly McKee and the other members who worked to set up the meeting and put things away. Without that support, we would not be able to hold the kinds of meetings we do. I appreciate your efforts so very much, my friends.

Support Group Meetings are important.

Block off the first Thursday of every month on your calendars and try not to schedule anything else that day! It's just one day a month!



MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the

Western Sizzlin' Steakhouse 17567 York Road, Hagerstown, MD

Thursday, February 6th, 11:45 AM

Our Speaker Will Be Kristen Francis Off Medications

Newsletter Highlights

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Hagerstown Parkinson's Support Group Meetings in 2020

Feb 6, Kristen Francis, Off Medications
Mar 5, Jacinta Handon, Adamas, with a Doctor
Apr 2, Katy Kobel, FOX Rehab, LSVT/BIG
May 7, Dr. Justin Martello, Movement Disorder
Specialist, Christiana Care Neurology
June 4, Lynda Janet, Somerford, Memory Loss
July 2, Group Discussion
Aug 6, Peter McMillin, Somerford, Resources
Sep 3, Robert Lindsay, Author, Communicating
Oct 1, Dr. Zach Levine, Neurosurgeon
Nov 5, Shannon Murphy, Physical Therapist
Dec 3, Our Holiday Party! No Speaker.

SPOTLIGHT

See <u>Page 5</u> for another piece written by our friend,

Dean Cook.

What is Parkinson's Disease

Parkinson's disease (PD) is a neurodegenerative disorder that affects predominately dopamine-producing ("dopaminergic") neurons in a specific area of the brain called substantia nigra. Symptoms generally develop slowly over years. The progression of symptoms is often a bit different from one person to another due to the diversity of the disease. People with PD may experience:

- Tremor, mainly at rest
- Bradykinesia
- Limb rigidity
- Gait and balance problems

The cause remains largely unknown. Although there is no cure, treatment options vary and include medications and surgery. While Parkinson's itself is not fatal, disease complications can be serious. The Centers for Disease Control and Prevention (CDC) rated complications from PD as the 14th cause of death in the United States.

The first step to living well with Parkinson's disease is to understand the disease and the progression.

(Continued on Page 2)

The Hagerstown Parkinson's Support Group

Group Facilitator:

Art Guyer, 240-625-2722 <u>4Parkinsons@gmail.com</u> 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 and Lunch

Our Caregivers' **Breakfasts** are on the 3rd Monday of every month. This month the breakfast is scheduled for **January 20th at 8:30 AM** at the **Hagerstown Family Diner**, located at 431 Dual Highway.

Caregiver's **Lunches** are on the 4th Monday of every month. This month the date will be **January 27th at 11:30**. It will be at the *Hagerstown Family Diner* also. Contact Art if you need information or directions.

Thank Your Board Members:

Mike Saterbak, Treasurer Carol Gaines, Secretary Ecile Shaw, Chaplain

Exercise at Any Age

Staying active is important throughout life. Regular exercise and physical activity help you stay strong and fit enough to keep doing the things you enjoy. No matter what your age, you can find activities that meet your fitness level and needs.

National Institute on Aging

Attention:

Information and content in this Newsletter is not intended to provide or substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your qualified health provider with questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this publication.

Senior Homes Activities

We had our last PD round table at Homewood at Williamsport on October 16, 2019; Carol Gaines and Art Guyer facilitated the session.

We have scheduled similar sessions at Homewood in 2020 on January 15th, April 15th, July 15th, and October 15th. Judy Fiery, Carol Gaines, and Art Guyer will try to continue this effort. There is a rumor going around that Linda Embly might even help out!

We still hope to continue these presentations with other senior facilities in the Hagerstown area.

Memory Café

Memory Café is a supportive environment for individuals with early-stage memory issues or Alzheimer's disease and other similar health problems. Join in for a <u>free lunch</u>, crafts, discussions and presentations. Please <u>help guarantee enough food is purchased by making a reservation</u>.

In Hagerstown, Memory Café meets on the 4th Thursday of every month at the Otterbein Church on East Franklin Street from 11:00 AM – 12:30 PM. The January meeting date is on the 23rd.



"We Guarantee Compassionate Care"

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. Carol Gaines is our Sunshine Committee of One and is responsible for sending out cards as appropriate. Call Carol at 301-824-3976 or contact Art if you know someone in need.

PD Group Bowling

Bowling is on hold until we get enough interest to make it worthwhile. If a half dozen people or so continue to want to bowl on a regular basis, I will schedule it again.

Birthdays in January

Happy Birthday to members who have birthdays this month. We announced your names and sing happy birthday to you at the meeting in January.

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

What is Parkinson's Disease

(Continued from Page 1)

It is possible to have a good to great quality of life with PD. Working with your doctor and following recommended therapies are essential in successfully treating symptoms by using dopaminergic medications. People with PD need this medication because they have low levels or are missing dopamine in the brain, mainly due to impairment of neurons in the substantia nigra.

It is important to understand that people with PD first start experiencing symptoms later in the course of the disease because a significant amount of the substantia nigra neurons have already been lost or impaired. Lewy bodies (accumulation of abnormal alphasynuclein) are found in substantia nigra neurons of PD patients.

Scientists are exploring ways to identify biomarkers for PD that can lead to earlier diagnosis and more tailored treatments to slow down the disease process. Currently, all therapies used for PD improve symptoms without slowing or halting the disease progression.

From Parkinson's Foundation

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Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

Handling Medical Issues (This will be our topic for the next several months)

Doctors' Appointments:

- Early mornings and right after lunch are the best times for scheduling doctors' appointments. They are less likely to be backed up at these times, however you also need to consider the time of day you are the most energetic, and medications are at peak.
- If you are anxious to see the doctor soon, tell the receptionist and ask to be put on the "short list" for cancellations.
- If you have a lot to talk about with your physician, make a consultant appointment so the doctor will allow enough time to discuss your concerns without being hurried. Be aware, however, the longer appointment may cost more.
- Be clear about what you want to say to the doctor. Do not introduce extraneous information into your description of symptoms. Write down your points in advance.
- Pay careful attention to your sleep patterns. Keep track of hallucinations or delusions.
- Write down what your doctor says. Remembering everything a doctor says can be difficult. It may be useful to bring someone
 with you to provide a second set of ears.

This and That Thoughts on my Mind by Art Guyer:

Well, of course you all are on my mind! I am here in Florida with Jan, enjoying the great weather and all of the fun activities we have planned for these two months. I am confident the board and other members are taking care of the meetings and any needs you all have at this time. Remember, though, I am just an email or text message away if you need something from me. I'll see you in March. By the way, I think you will all get to meet Jan in May. Let's pack the house for her.

Also, I just heard our friend, Charles Emery, fell and broke his hip. He has had a hip replacement and will need substantial rehab over the next several months. Please keep Bonnie and Charles in your prayers and thoughts.

Take care..... Art

Four-State Alliance Support Group News:

Next 4SAPS Leader Board Meeting: March 14, 2020; Steve Silvious will be facilitating this meeting.

Friends in Frederick PD Support Group: The next meeting of this support group will be on **Wednesday**, **January 15**, **2020**, at 1:00 PM. Their speaker will be Macky Stafford from Acadia Pharma, the makers of Nuplazid. Contact Janet or Steve Silvious at 301-831-5609 for directions and more information.

PD Support Group of Frederick: The next meeting of this support group will be **Saturday**, **January 18**, **20**20, at 12:00 PM. There speaker will be Dr. John Baker, from the Baker Rehab Group. They meet at the YMCA at 1000 N. Market Street in Frederick, MD. Contact: Louise Houtz, houtzmom@hotmail.com for more information.

Caregiver Support Group: The Commission on Aging has a *Caregiver Support Group* that meets quarterly. It is free to attend and open to the public. Contact: Cebrina Young at 301-790-0275 x240 for information and/or directions.

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Heads Up, Caregivers! Five Techniques That Quickly Relieve Caregiver Anxiety

Caregivers can feel overwhelmed by anxiety. Caring for a loved one is a tough job. The stress can build up and suddenly get to a point where the anxiety and emotions intensify until you feel completely overwhelmed. You could be filled with anxiety, fear, or nausea. To quickly break out of those panicked negative spirals, here are 5 ways to stop caregiver anxiety in its tracks. Called grounding techniques, they plant you firmly in reality, in the present moment. The simple exercises force you to focus on concrete things in the real world. Taking your mind out of anxiety-mode gives you the ability to refocus and find your reservoir of strength and calm.

Do as many of these exercises as you need, as many times as you need, until the anxiety subsides, and you feel better.

1. Use the 54321 technique

- Name 5 things you can see (table, towel, cushion, etc.)
- Name 4 things you can feel (my feet on the floor, my back against the chair, the sun on my face, etc.)
- Name 3 things you can hear right now (the radio playing, birds chirping outside, etc.)
- Name 2 things you can smell right now (trees and flowers from outside, soup cooking on the stove)
- Name 1 good thing about yourself (I'm generous with my kindness)

2. Touch and describe an object

• Find an object around you (mug of tea). Describe it in detail as if you're explaining it to someone who has never seen it before. For example: This is a mug of tea. It's a ceramic column that's hollowed out so it can hold liquid. It's a pale blue color and there is a handle that fits four fingers. It has tea inside, a hot liquid made from leaves. Repeat with various objects until you feel calmer

3. Play a memory game

Ask yourself questions that involve memory or concentrated thinking. For example:

- Sing (or say) as much of your favorite song as you can without the music
- Name as many types of dog breeds as you can (or cat, bird, etc.)
- How many places have you visited in your lifetime?

4. Repeat a mantra

During a calm, relaxed time, make a list of positive sayings or mantras that help you calm down and return to the present moment when anxiety makes you feel panicked. Keep this list close to you so you can pull it out as soon as you feel the need. For example:

- This moment will pass and I will be OK
- I am safe and well
- These feelings will pass and things will be OK

5. Do square breathing

When you're stressed, you may change your breathing. You might take rapid, shallow breaths or hold your breath instead of taking the slow, deep breaths your body needs to get plenty of oxygen and kick-start the relaxation process. Square breathing helps you focus in a way that helps your body calm itself. Draw breaths in all the way down to your toes and push all the air out when you exhale.

With your finger, slowly trace the shape of a square in front of you. Keep your eyes on that finger as it moves.

- As you draw the first side, breathe in deeply for 3 seconds
- With the second side, hold your breath for 1 second
- With the third side, breathe out for 3 seconds
- With the fourth side, hold for 1 second

Feel free to vary the timing of the square's sides to make it comfortable and relaxing for you – the breaths just need to be slow and deep. Repeat the square and the breaths for as long as it takes to slow your heart rate and calm your mind.

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Here is the piece written by Dean Cook to honor his friends Jay and Betty Stouffer.

Friends By Dean Cook

I have these friends, you see, a man and wife I've known for about six years. But they became my friends immediately because I recognized a goodness in them that wouldn't let go. Goodness can be like a magnet that way if you're inclined to appreciate goodness. Do we get kinder as we get older? I think we do. We appreciate not only the road we have traveled but the road others have traveled.

And, speaking of roads traveled, this man, who is my friend, has traveled almost 2400 miles with me over the last four years. We go to Johns Hopkins in Baltimore twice a year, mostly to participate in studies that facilitate research for Parkinson's Disease. It's not fun. We leave early and fight traffic coming and going and while we're there, we submit to a battery of tests, both physical and mental. And we allow the wonderful Hopkins staff access to whatever fluids they want to extract from our bodies. Fluids are

important, they tell us. But there is a benefit to all this because my friend and I get a lot of attention from a lot of very smart people. And we also get excellent oatmeal.

During those trips, my friend reveals some things that allow me to know what kind of man he is. He's over 80 years old and he's been married to his wife, my other friend, for over 60 years. He is a landlord who is very kind to his tenants; he started the first little league program in the community where he grew up and still lives; until recently, on his own time and by himself, he would deliver medical equipment, sometimes heavy and bulky, to people in need; and for many years he was an officer in a charitable organization that distributed thousands of dollars to those less fortunate. On many Saturdays, these two friends of mine can be found dishing out scrambled eggs and gravy to several hundred people to raise money that will go to help others. At Christmastime, for the same reason, he sells trees.

I never heard him brag about these things or be the one to bring them up. They just surfaced during normal conversation. Most importantly, he makes that trip to Baltimore with me every time. He has other health issues and I know there are days he doesn't feel well. But he does it.

The reason I bring all this up is that during our last trip to Hopkins, there was an envelope with my name on it laying on the seat of my truck. I opened it and found a gift certificate to a restaurant my wife and I like. And there was a card. On the front of the card was the following message: "It takes a special kind of person to care enough to take the time for others, to do whatever it takes to help somebody else." I'm not a keeper of cards, or mementos, or photographs. But I will keep this one.



As a matter of fact, Betty and Jay Stouffer, I just may send the card back to you one day...be-cause it describes you better than me.

SPECIAL REQUEST: Judy Frantz is looking for someone to help her Mother with her ADLs. Offering free Room & Board and a small stipend. Lives in Hagerstown across from North High. Contact me if you or someone you know is interested.

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Awards for 2019

It's time to nominate two individuals for Outstanding Member of the Year. These awards recognize special individuals in our Support Group for their outstanding contributions, dedication and assistance to our support group family during the past year. Separate awards will be made to a member who has Parkinson's Disease and a member who is a caregiver.

Previous awards have been presented to Art Guyer, Dave DeHaven, Connie Hipp, Dean Cook, Carol Cook, Ecile Shaw, Jay Stouffer, Carol Gaines, Vi and Frank McConnell, Mike Saterbak, and Ragan Shaw. *They are not eligible for a second award.*

Complete the following form and return it to Mike Saterbak by the end of the February meeting. Please be brief, but specific. We will present these awards at our March 2020 meeting along with new Red Lanyard awards.

Name of Nominee with Parkinson's Disea	<mark>;e</mark> :	
Describe briefly why you recommend this indi	vidual for this award:	
Name of Nominee who is a Caregiver:		
Describe briefly why you recommend this indi	/idual for this award:	

Focused Ultrasound

Tremor is a neurological problem that occurs with many illnesses such as Parkinson's Disease and Essential Tremor. When the tremor is of moderate to high severity, it affects eating, drinking, writing, and other activities that require controlled and accurate movement. The result is a significant decrease in quality of life.

Many patients with a significant tremor that does not respond to medication are offered a surgery to implant a pulse generator and electrodes in the brain, referred to as Deep Brain Stimulation (DBS).

As an alternative to this invasive treatment, the Israeli company, INSIGHTEC, invented a revolutionary non-invasive treatment that produces significant and immediate relief of the tremor in a single treatment. The procedure, performed on the Exablate system in the MRI room by means of a focused ultrasound (FUS), is performed while the patient is awake and involves no anesthesia, no incisions in the scalp, and no burr holes through the skull or insertion of electrodes into the brain.

The innovative procedure is approved for commercial use in Europe and is offered in Israel at the Rambam Medical Center campus.

Approximately 200 patients worldwide have been treated by the procedure, among them 40 patients at Rambam with a 90% success rate.

Click here for more information.

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Reminders of upcoming events as of Friday, January 03, 2020

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	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 Springfield Room, Bethany Village West, Mechanicsburg, PA	Dan Yother, 304-676-2053 oldred714@verizon.net Carol Cressler, 717-877-0624, cjcressler4040@gmail.com
Hagerstown Parkinson's Support Group Caregiver's Breakfast	3 rd Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Hagerstown Parkinson's Support Group Caregiver's Lunch	4 th Monday @ 11:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Friends in Frederick PD Support Group 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
PD Support Group of Frederick	3 rd Saturday @ 1:00 PM YMCA - 1000 N. Market Street, Frederick MD	Louise Houtz houtzmom@hotmail.com
Cross Keys Parkinson's Education & Support Group	3 rd Thursday @ 1:00 - 3:15 PM Cross Keys Village, New Oxford, PA	Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net
Carroll County Parkinson's Support Group	2 nd Wednesday, every 2 months (Even Months, excluding December) @ 1:00 PM, Shauck Auditorium, East Pavilion, 291 Stoner Avenue, Westminster, MD	Christina McGann, 410-871-6165 CMcGann@carrollhospitalcenter.org

OTHER EVENTS:

NOTE: Unless otherwise noted, Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.

- Monday, January 20, 2020, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, January 23, 2020, 11:00 AM 12:30 PM Hagerstown Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. RSVP (required) to David Kukor at 301-639-3166 or dkukor@ahcglobal.com.
- Monday, January 27, 2020, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, February 6, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Kristen Francis, Off Medications
- Monday, February 17, 2020, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Monday, February 24, 2019, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.

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- Thursday, February 27, 2019, 11:00 AM 12:30 PM Hagerstown Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. RSVP (required) to David Kukor at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, March 5, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Jacinta Handon, Adamas, with a Doctor
- Monday, March 16, 2020, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Monday, March 23, 2020, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, March 26, 2019, 11:00 AM 12:30 PM Hagerstown Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. RSVP (required) to David Kukor at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, April 2, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Katy Kobel, FOX Rehab.
- Monday, April 20, 2020, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, April 23, 2019, 11:00 AM 12:30 PM Hagerstown Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. RSVP (required) to David Kukor at 301-639-3166 or dkukor@ahcglobal.com.
- Monday, April 27, 2020, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, May 7, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker Dr. Justin Martello, Movement Disorder Specialist, Christiana Care Neurology.
- Monday, May 18, 2020, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Tuesday, May 26, 2020, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, May 28, 2020, 11:00 AM 12:30 PM Hagerstown Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. RSVP (required) to David Kukor at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, June 4, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker Lynda Janet, Somerford, Memory Loss.
- Monday, June 15, 2020, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Monday, June 22, 2020, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, June 25, 2020, 11:00 AM 12:30 PM Hagerstown Memory Café: Free lunch, crafts and meeting at the Otterbein Church on East Franklin Street in Hagerstown. RSVP (required) to David Kukor at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, July 2, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Group Discussion

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 <u>must write that</u> to assure the money goes into our MAPS account. Mail donations to: MAPS Treasurer, Box 450, Brooklandville, MD 21022