Hagerstown, MD and the Four-State Area

Monthly Newsletter

November 2017

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

Volume 7, Issue 11

This Month's Meeting

November Meeting

Dean's Corner

There were **58** individuals at our October meeting including **6** new attendees. Dr. Stephen Ryan, PT, DPT, owner of Ryan Physical Therapy in Hagerstown, was our featured speaker. Dr. Ryan spoke about the benefits of physical therapy for PD patients and specifically the LSVT/BIG program. He explained the concept, outlined the process, and gave a few demonstrations including one exercise using one of our members.

Several of our members have been or are currently clients of Dr. Ryan. His contact information is:

Ryan Physical Therapy 1190 Mount Aetna Road Hagerstown, Maryland 21740 301-797-4572

Lynn Shriver 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 a moving prayer before lunch.



Dr. Kelly Mills, a Movement Disorder Specialist from Johns Hopkins University Hospital is our speaker next month. Last year he packed the room and set a new attendance record. We expect he will

be a big draw again this year because of his ability to discuss Parkinson's Disease in a manner that we can all understand. Come early to get your favorite seats!

The Hagerstown Parkinson's Support Group

Group Facilitator:
Art Guyer
22215 Troy Lane
Hagerstown, MD 21742
240-625-2722
4Parkinsons@gmail.com

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the

Western Sizzlin' Steakhouse 17567 York Road, Hagerstown, MD

Thursday, November 2, 2017, 11:45 AM Featuring

Dr. Kelly Mills, Johns Hopkins Movement Disorder Specialist

Newsletter Highlights

Tips for Making Life Easier (Page 3)
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Fall Picnic Photo and Holiday Party Info (Page 5)
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Detailed Event Listing (Pages 7 & 8)

Future Meetings:

2017

Nov 2, Dr. Kelly Mills, MDS, Johns' Hopkins Dec 7, Christmas Party & Gift Exchange

2018

Jan 4, Michael G. Day, Elder Care Attorney

Feb 1, Dr. Liana Rosenthal, MDS, Johns Hopkins

Mar 1, Group Discussions

Apr 5, Arita McCoy, RN, BSN, John Hopkins

May 3, Dr. Ankur Butala, Neuropsychiatrist, JHU

Jun 7, Dr. Gerald "Dave" Podskalny, FDA Jul 5, TBD

Aug 2, TBD

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!

September Open Forum

Art and I received favorable comments on our September meeting and the wide range of topics discussed. It was slow at first but as we got going a number of interesting topics common to all of us PD folks, including caregivers, emerged. It has occurred to me on several occasions that our real partners in this journey are our spouses and other family members and significant people in our lives who don't experience what we go through but make a valiant effort to understand. And I think every one of us who has PD would agree that because of the finicky and inconsistent nature of the disease it is sometimes difficult for us to explain it. So a BIG SHOUTOUT to you caregivers and other loved ones who stick by us day in and day out, tolerate us on those days we have trouble talking and walking, understand that we may need to stay in bed another hour or two, and accept us unconditionally.

Dean

Dean Cook, Meeting Facilitator Hagerstown Parkinson's Support Group 497 Hogan Drive

Martinsburg, WV 25405 Phone: 304-268-1623 Email: home2wv@yahoo.com

ATTEND A SUPPORT GROUP MEETING!



Local Support Group Information is on Page 7.

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, October 16th at 8:30 AM at the Hagerstown Family Diner. This restaurant is located at 431 Dual Highway. 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 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.

Memory Café

Memory Café is a supportive environment for individuals with early-stage memory issues or Alzheimer's disease and other similar health problems. It is a safe and relaxed place where families, friends and health professionals come together for a unique blend of educational and social interaction. Families and friends are encouraged to join in for free lunch, games, discussions and presentations. Please help guarantee enough food is purchased by making a reservation.

In Boonsboro, Memory Café meets on the 3rd Tuesday of the month at 11:30 AM – 1:00 PM. (October 17th). The location is the Hospice Community Life Center at 28 N. Main Street. RSVP to Terry Miller at 301-471-314 or tmiller@ahcglobal.com. Space is limited; reservations required.

In Hagerstown, Memory Café meets the 4th Thursday of every month at the Otterbein Church on East Franklin Street from 11:30 AM – 1:30 PM. (October 26th). Contact Dave Kukor at 301-639-3166 or dkukor@ahcglobal.com for reservations (required) and information.

PD Group Bowling

Bowling has resumed on a regular monthly basis. Dean Cook has worked it out with Southside Bowl that they will provide lanes for our group on the third Thursday of every month at 1 PM. Please join us at Southside Bowl, 17325 Virginia Avenue, Hagerstown. The games will continue to be \$2.00 and the bowling shoes free. This month the date will be October 19th.

Birthdays in October

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 required, 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. Carol Gaines has volunteered to be our new Sunshine Committee of One and is now responsible for sending out cards as appropriate.

Thanks Carol.

Call Carol at 301-824-3976 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)

And this is the final segment of "Looking Good and Feeling Better" - Hosiery and Footwear:

- Choose the right shoes. If you have a shuffling gait, soft rubber soles make walking more difficult, especially on carpeting, where the soles act like Velcro and can cause you to trip. Hard leather shoes can be slippery on linoleum or tile floors.
- Use elastic shoelaces in place of normal laces so you will only have to tie your shoes once. Just slip your shoes on and off.
- Have a shoemaker convert your traditional shoes into Velcro-closing shoes. Or buy shoes that already have a Velcro-closure
 or those that slip on, like loafers.
- Put on your shoes with a long-handled shoehorn to minimize bending and reaching.
- Wear tube socks because they are easier to put on than socks that are shaped like a foot. Sew loops into the inside of each sock and use the loops to pull on the socks.
- Sprinkle cornstarch on the bottom of your feet and around the heel area to make pulling on nylon stockings or socks easier.
- Alter your slacks to accommodate an ankle-foot orthotic brace. If you wear an ankle-foot brace that fits inside a shoe and goes up the calf, it will be easier to dress if you sew a 7-inch zipper into the inside side seam of your slacks.

This and That Thoughts on my Mind by Art Guyer:

I've been thinking about our outstanding members. I focus on them especially during this time of year because of the awards coming up. I'd like you all to think about those in the group who always put out that extra effort to help the group or an individual member. See page 4 for more information and a form you can use to submit nominations. It is going to be tough this year because we have quite a few who I think qualify.

Take care..... Art

News from the Chambersburg Parkinson's Support Group: The group will hold its next meeting on October 20th at 4:00 PM at *Physical Therapy, Etc.*, located at 142 Farmhouse Lane, Chambersburg, PA. Their speaker will be Gina Rowland, Speech Pathologist and Certified LSVT Speech Therapist. All are welcome to attend. The contact for this group is Kathy Smith, 717-377-8320.

News from the Friends in Frederick PD Support Group: The next meeting of this support group will be on October 18, 2017. You should contact Janet or Steve Silvious 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!

Challenges You as a Caregiver Are Likely to Face

There are many challenges that a person with Parkinson's disease confronts. First, the disease can vary from day to day. There will be times when he or she can function almost normally and then other times when he or she will be very dependent. This is a natural part of the disease. But it can make a caregiver feel the person is being unnecessarily demanding or manipulative. Keep in mind that Parkinson's is unpredictable and each day can pose new challenges for you and your loved one.

Also, keep in mind that Parkinson's is a progressive disorder. While medications and surgery can provide significant relief of symptoms, they do not stop the progression of the disease.

Depression is also very much a part of the disease. It is important to recognize the signs and symptoms of depression so you can help your loved one seek treatment promptly. And, if you are feeling depressed and having trouble coping, it's just as important to get care for yourself.

Communicating with Your Loved One: Parkinson's disease can make verbal communication very difficult for your loved one. That can get in the way of your ability to care for his or her needs. Here are some ways that can help you better understand your loved one:

- Talk to your loved one face-to-face. Look at him or her as he or she is speaking.
- In the case of advanced disease, ask questions that your loved one can answer "yes" or "no."
- Repeat the part of the sentence that you understood. (For example, "You want me to go upstairs and get the what?")
- Ask your loved one to repeat what he or she has said, or ask him or her to speak slower or spell out the words that you did
 not understand.

Nomination for Outstanding Members of the Year – 2017

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 went to Dave DeHaven, Connie Hipp, Dean Cook, and Ecile Shaw. They are not eligible for a second award.

Complete the following form and return it to Art Guyer or Dean Cook by the end of our December meeting. Please be brief, but specific. We will present these awards at our January 2018 meeting.

sent these awards at our January 2018 meeting.
Name of Nominee with Parkinson's Disease:
Describe briefly why this individual deserves this award:
Name of Nominee who is a Caregiver:
Describe briefly why this individual deserves this award:

Use another sheet of paper if necessary.

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Fall Picnic



The Support Group held its fall picnic on September 15, 2017. Twenty-six persons associated with Parkinson's Disease enjoyed the day at Martin "Marty" L. Snook Memorial Park. The weather was perfect for the outing and everyone enjoyed fried chicken from AC&T accompanied by a variety of dishes and desserts provided by the participants. The host, Art Guyer, welcomed the group and awarded a number of prizes including 10 nice mums. The co-host, Dean Cook, called bingo for the group, giving away about 30 wrapped prizes brought by the members.

Attending the picnic were: Art and Doris Guyer, Dean Cook, Mike and Marci Saterbak, Ecile and Ragan Shaw, Bill Storms, Jay and Betty Stouffer, Chuck and Aura Bihun, Hugh and Linda McSweyn, Vi McConnell, Marie Fogarty, Talia Valencia, Charles and Betty Martin, Edie Johnston, Chet and Rose Fabijanski, Judy and Sam Fiery and Gloria and Carl Rith

Holiday Party

Date: Thursday, December 7, 2017

Our December meeting will be our annual holiday party and we will not have a speaker.

We hope to have some games and carol singing. Everyone should please bring a wrapped present and we will have a blind exchange of gifts. Gifts can be in the \$5 -- \$10 range and should be somewhat appropriate for a man or a woman.

We would hope to get a couple volunteers to arrange some games and to handle present distribution.

For more information, contact: Dean Cook or Art Guyer.



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Thinking about Newly Approved Therapies

Posted by <u>Rachel Dolhun, MD</u>, September 13, 2017 MJFF Webpage

The FDA recently approved a new medication for levodopa-induced dyskinesia (Gocovri), making it the fifth new drug for Parkinson's symptoms in just over two and half years. This steady flow of market-bound therapies shows no signs of slowing -- therapies for sudden "off" periods (when symptoms unexpectedly return) are close to the FDA's doorstep and levodopa reformulations to smooth out daily fluctuations are completing clinical trials.

New drugs represent the successful culmination of many years, dollars and research volunteers' efforts, and for people with Parkinson's, they expand treatment options and potentially provide an alternative route for symptom control.

New therapies bring questions, though, as to whether and how to incorporate them into your regimen. Fenna Phibbs, MD, MPH, associate professor of neurology and director of the Movement Disorders Deep Brain Stimulation Program at Vanderbilt Medical Center, talked with us about these considerations.

The Michael J. Fox Foundation (MJFF): As new Parkinson's drugs are approved, what should patients know?

Fenna Phibbs (FP): New isn't necessarily better. Just because a new therapy is approved doesn't mean it's right for everyone, or that you have to change your regimen. Know what symptoms each new medication treats so that you can discuss with your doctor whether it's an appropriate option for you.

If your symptoms are well controlled and you aren't experiencing bothersome side effects, it's unlikely you and your doctor will want to switch your medications. If, on the other hand, your symptoms affect your day-to-day living or your medications are not ideal (i.e., they cause significant side effects or require frequent dosing that's hard to maintain), you may want to contemplate an alternative. (And that may be a new therapy or one that's been around for a while.)

MJFF: What questions should patients ask when thinking about a new medication?

FP: Here are some you should definitely consider asking:

- What symptoms does it treat? Do you have these symptoms? If so, are they currently controlled? Or do your medications cause troublesome side effects? (In other words, do you even need to consider this medication for yourself?)
- How much benefit might you get from the medication?
- What are the drug's potential side effects? Might it interact with other medications?
- How does it work? Is that different from your current therapies?
- What, if any, are the other available options?
- How would you take it? (Would it replace one of your current medications or be added to your regimen?)
- How much does it cost? Does insurance cover it?

MJFF: How do doctors and patients decide if they should try a new therapy?

FP: We work together, but ultimately, I defer to my patients because they are the ones who take the medication every day. When symptoms impact quality of life, that may be a good time to discuss change. Change just to make a change isn't good, so we make sure we know the goal. We decide what symptom we want to address and then, after starting a new therapy, we watch over the next week or two to see whether this improves, worsens or stays the same.

MJFF: Any last thoughts on new therapies?

FP: Always ask your physician about their experiences with new therapies. It can be hard to get a real sense of what a medication could do for you just by reading about it online or hearing its benefits touted on the news. Your doctor can put it in context for your individual situation and relay what they've seen when using the medication with other patients.

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Reminders of upcoming events as of Saturday, October 07, 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 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 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 3 rd Friday, every 2 months (Even Months) @ 4 PM at Physical Therapy Etc. 142 Franklin Farmhouse Lane, Chambersburg, PA	Kathy Smith, 717-377-8320, Kathy.smith@embarqmail.com

OTHER EVENTS:

- Monday, October 16, 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.
- Tuesday, October 17, 2017, 11:30 AM 1:00 PM, Boonsboro Memory Café: Free lunch, crafts and meeting at the Hospice Center, 28 N. Main Street, Boonsboro, MD 21713. RSVP (required) to Terry Miller at 301-471-3146 or tmiller@ahcglobal.com.
- Thursday, October 19, 2017, 1:00 PM 4:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown. Contact Dean Cook for information at 304-268-1623 or by email at home2wv@yahoo.com.
- Thursday, October 26, 2017, 11:30 AM 1:00 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, November 2, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Dr. Kelly Mills, Movement Disorder Specialist, JHU. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.

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- Thursday, November 16, 2017, 11:30 AM 1:00 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, November 16, 2017, 1:00 PM 4:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown. Contact Dean Cook for information at 304-268-1623 or by email at home2wv@yahoo.com.
- Monday, November 20, 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.
- Tuesday, November 21, 2017, 11:30 AM 1:00 PM, Boonsboro Memory Café: Free lunch, crafts and meeting at the Hospice Center, 28 N. Main Street, Boonsboro, MD 21713. RSVP (required) to Terry Miller at 301-471-3146 or tmiller@ahcglobal.com.
- Thursday, December 7, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Holiday Party and Gift Exchange. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722
- Thursday, December 14, 2017, 11:30 AM 1:00 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, December 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.
- Tuesday, December 19, 2017, 11:30 AM 1:00 PM, Boonsboro Memory Café: Free lunch, crafts and meeting at the Hospice Center, 28 N. Main Street, Boonsboro, MD 21713. RSVP (required) to Terry Miller at 301-471-3146 or tmiller@ahcglobal.com.
- Thursday, December 21, 2017, 1:00 PM 4:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown. Contact Dean Cook for information at 304-268-1623 or by email at home2wv@yahoo.com.
- Thursday, January 4, 2018, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker is Michael Day, Elder Care Attorney. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Monday, January 15, 2018, 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.
- Tuesday, January 16, 2018, 11:30 AM 1:00 PM, Boonsboro Memory Café: Free lunch, crafts and meeting at the Hospice Center, 28 N. Main Street, Boonsboro, MD 21713. RSVP (required) to Terry Miller at 301-471-3146 or tmiller@ahcglobal.com.
- Thursday, January 18, 2018, 1:00 PM 4:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown. Contact Dean Cook for information at 304-268-1623 or by email at home2wv@yahoo.com.
- Thursday, January 25, 2018, 11:30 AM 1:00 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, February 1, 2018, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Dr. Liana Rosenthal, Movement Disorder Specialist, Johns Hopkins. 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 <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