Hagerstown, MD and the Four-State Area

## **Monthly Newsletter**

**April 2017** 

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

Visit us on Facebook

### This Month's Meeting

There were **48** attendees at our March meeting, including **5** new people. This meeting featured Ms. Jaclyn Garrish, a speech-language pathologist from Total Rehab in Hagerstown. She gave an excellent presentation about PD and speech and swallowing issues.

**Ecile Shaw** won the \$10 gift certificate donated to the group by the owners of the Western Sizzlin' Restaurant. Thanks to Paul and his family for being so generous.

Thanks to **Ecile Shaw** for delivering the prayer before lunch.

## APRIL IS PARKINSON'S DISEASE AWARENESS MONTH.

#### NOTE: MEMORY CAFÉ'S NEW HOURS ARE FROM 11:30 am TO 1:00 pm. SEE PAGES 7 AND 8 FOR MORE DETAILS.

Dean Cook, Meeting Facilitator Hagerstown Parkinson's Support Group 497 Hogan Drive Martinsburg, WV 25405 Phone: 304-268-1623 Email: home2wy@yahoo.com

# April Meeting

### MARK YOUR CALENDARS

Join us for our next Parkinson Support Group Meeting at the

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, April 6, 2017, 11:45 AM Featuring

#### Sandra Mertz

Neurogenic Orthostatic Hypotension A disorder that is defined as low blood pressure that occurs upon standing.

#### **Newsletter Highlights**

Tips for Making Life Easier (<u>Page 3</u>) Heads Up, Caregivers! (<u>Page 4</u>) Poem by Dean Cook. A Must Read! (<u>Page 5</u>) Experimental Drug Reduces "Off" Time (<u>Page 6</u>) Detailed Event Listing (<u>Pages 7 & 8</u>)

#### **Future Meetings**

2017

Apr 6, Sandra Mertz, Neuro. Ortho. Hypotension May 4, Patients & Caregivers Breakout Sessions Jun 1, Colleen Brown, RN, BSN, Medtronic DBS Jul 6, Dory Kennedy, Right at Home Aug 3, TBD 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

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!

### Volume 7, Issue 4

### 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 16<sup>th</sup> at Snook's Park, Pavilion 4. 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 16<sup>th.</sup>

**Bowling** – We would like to get our bowling activity back on track. There have been times when we've had as many as 10 or 12 bowlers but the attendance has dropped off recently. This month we will reserve some lanes for Friday, March 24<sup>th</sup>. 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.

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 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 3<sup>rd</sup> Monday of every month.

This month the breakfast is scheduled for Monday, March 20 at 8:30 AM at the <u>Hagerstown Family Diner</u>. 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)

### **Cancellation Due to Weather**

Our weather cancellation policy is

based on the Washington County School System. If the Washington County Schools announce they are closed for <u>the entire day</u>, then we will not have our regular monthly meeting. Also, I will send an email out by midmorning if it is to be cancelled; those without email should listen to the TV and Radio for the school

Radio for the school announcements.



### MAPS Ambassado

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.

#### PFNCA 2017 Symposium

Registration for the 2017 Parkinson Foundation of the National Capital Area Symposium is now open. The program will be held March 25th in Falls Church, Virginia. You can learn more and register by clicking here or by calling the PFNCA office at (301) 844-6510.

### **PD Group Bowling**

We will be bowling on March 24th. 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 March**

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.

Frank and Vi McConnell's



Granddaughter is at Julia Manor recovering from serious injuries in an autombile accident. Please keep the family in your thoughts and prayers.

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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: The Bedroom

**Use baby monitors to hear a person with PD who is in bed.** The monitor's transmitter sits on the bedside table and the receiver goes in another room for remote listening. Some monitors have portable receivers so you can listen to the person as you move around the house.

There are **other electronic devices** that can be very useful that I (Art Guyer) have tried. One we bought can be used in the bed or in a chair or other sitting places. It is an alarm device that has a cord on it that attaches the patient's clothing. If the patient moves too much the cord will separate from the device setting off an alarm to warn caregivers. We also use simple FRS radios (walkie-talkies). The patent only has to push the call button and the other radio will make a noise alerting the caregiver the patient needs assistance. The third thing I would recommend for patients who have balance issues but still try to get out of bed is a wireless/cordless bed alarm. This device has a unit that is put beside the patient's bed that detects movement. When that happens it sets off an alarm at the receiver that would be kept close to the caregiver; no alarm is sounded in the patient's room.

Help the person with PD feel relaxed in the bedroom by implementing a few of these tips:

- Give the person a back or leg massage.
- Keep a favorite blanket or pillow on the bed for comfort and security. Don't purchase new linens without checking to see of the person with PD likes them. Bringing unfamiliar items into the environment can be very upsetting to people with PD who are confused or have dementia.
- Use a night light or leave the bathroom or hall light on to help keep the person with PD oriented to where he or she is.

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

As some of you know, my mother passed away on Friday, March 3 between 10:00 and 11:00 AM. She was 94 years old, but in good health physically; her vitals were better than mine when she visited her doctor. She had memory issues but other than that she was in pretty good shape. She lived alone in her house and took care of herself for the most part. My sister, who found her that morning, lives across the street and saw her every day to make certain she had her medications and would often take her out for lunch. That was the plan that morning. It has been an extremely hard year for Doris and I and for many of you. I want to thank you all for your support once again.

Take care ..... Art

**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.

Save the Date for the next meeting scheduled for April 11 @ 10:00 a.m. (Call 301-790-0275 ext. 221) Topic: Dynamics of Family Caregiving and the roles that Family Member takes on. Speaker: Chis Fisher, Delegating RN at Right at Home In-Home Care and Assistance.

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## Heads Up, Caregivers: The Caregiver's Role in Parkinson's Disease Treatment and Care

EverydayHealth.com By Dennis Thompson, Jr.

As a Parkinson's disease caregiver, you are the medical team's eyes and ears, letting them know whether your loved one's Parkinson's disease treatment is working or needs to be changed.

PD is a highly individualized disorder, in which no two people have the exact same symptoms. As a caregiver, you are witness to what your loved one is going through — that puts you in the perfect spot to communicate those symptoms effectively to the patient's neurologist or primary care doctor. By doing so, you can make a tremendous contribution to your loved one's Parkinson's disease treatment.

It goes the other way, too. You also can help execute the doctor's treatment plan by making sure the patient takes medication on time and completes all necessary exercises.

#### Caregivers and Parkinson's Disease: Monitoring Parkinson's Medication

Parkinson's medication works on the biochemistry of the brain — very precise dosages must be delivered at precise times. Taking Parkinson's medication even a few minutes late can result in debilitating symptoms like muscle rigidity and tremors.

On top of that, Parkinson's patients might take other drugs to deal with issues like depression and sleeplessness. The patient faces the prospect of taking many different drugs at varying times, and even a minor slip in dosing could cause symptoms to re-emerge. You can do your loved one a huge service by crafting a schedule for all the medications taken, and making sure the plan is followed.

#### Caregivers and Parkinson's Disease: Monitoring Exercise and Physical Therapy

New research has found that exercise might be very valuable to people with PD — perhaps even as beneficial as medication. Exercise helps keep the muscles and joints limber and appears to promote neurological health in Parkinson's patients. In addition, physical therapy can help your loved one maintain independence for as long as possible. You can help by assisting with home-exercise programs or getting to physical therapy on a regular basis.

#### Caregivers and Parkinson's Disease: What to Watch For

Caregivers serve an invaluable role as the doctor's day-to-day eyes and ears. As a caregiver, you should watch out for the following:

- Any increase in symptoms. If your loved one is taking medication properly but the number or severity of symptoms is increasing, you need to report it to the doctor. The patient might need to be put on different Parkinson's medication or may need to take a higher dose of current Parkinson's medication. Specific symptoms you should watch for include tremors (uncontrollable shaking) and rigidity (trouble moving the limbs). You also should tell the doctor if your loved one is having problems walking, talking, swallowing, or remembering information.
- Changes in mood. Depression is a problem for at least half of all Parkinson's patients it's so prevalent that doctors suspect depression might be a true symptom of the disease. Patients also are known to suffer from periods of denial, anxiety, and stress. You should pay attention to these moods and talk about them with your loved one and the doctor. The patient might benefit from antidepressant medication or from counseling.
- Sleep problems. Parkinson's patients tend to have a troubled relationship with sleep. The disease and their Parkinson's medication can make them incredibly drowsy during the day and then keep them up all night. Fatigue can worsen symptoms and prevent the person from focusing on their own well-being. If you notice your loved one isn't sleeping well, talk about it with the patient and the doctor. The doctor might prescribe a sleep aid or adjust the Parkinson's medication. You also can help by keeping the patient active during the day and by establishing a regular bedtime routine that promotes quality sleep.

And remember, your role as caregiver is vital to the well-being of your loved one. Your observations can help the doctor evaluate the Parkinson's disease treatments and decide whether they should be changed, which will undoubtedly help your loved one's situation.

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Dean Cook wrote this poem in the "wee hours of the morning when he could not sleep." It brings tears to my eyes every time I read it. Thanks, Dean, for giving us permission to print it.

### I'm Where I Need to Be

By Dean Cook

Another meeting is about to begin and as I look out over the crowd, Something stirs inside my heart that makes me very proud. And as I search for the answer to that question the brain so often sends, A voice gently nudges me, "You're here with 50 friends."

For the next two hours I'm where I need to be. With people who share this part of my life...people just like me. People I can hug for a few seconds, knowing they understand, Realizing we share a bond, hand in hand.

On this day I look at each and every one of you And wonder where your individual thoughts are going to. What personal battles you've fought since last we met And, because you're my family and I care, those you haven't confronted yet.

I look at you and know there is something we'll always share-That big unanswered question just hanging out there: "Why have I been singled out...what could I have possibly done?" And, although we'll never know the answer to that...at least we've all become one.

I see the sly grins and ornery looks on some familiar faces, As folks arrive and greet each other and sit in the same old places. And I'm reminded of the thought I had before...I'm where I need to be... With people who share this part of my life...people just like me.

It's funny how thoughts occupy your brain, Sometimes like a waterfall...sometimes like gentle rain. And today I'm thinking, if I'm making this trip, I want to be with you. Together, perhaps we'll open doors that we can all walk through.

We'll continue to take what life hands us in our normal stride. And I'm reminded of the words in that old song "Side by Side." "We ain't got a barrel of money...Maybe we're ragged and funny, But we'll travel along....Singing a song...Side by side.

I don't know what's coming tomorrow...Maybe it's trouble and sorrow, But we'll travel the road...Sharing our load...Side by side. Through all kinds of weather...What if the sky should fall? Just as long as we're together...It really doesn't matter at all."

And, finally, as Ecile says Grace, I look around and see the serenity on each person's face. And I'm comforted by that recurring thought, you see: I'm where I need to be...with people just like me.

Carol and I thank you for being part of our lives.



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### New Support for Therapy that Reduces "Off" Time

Parkinson Disease Foundation -- January 12, 2017

A new study finds that the experimental drug opicapone significantly reduces "off" time for people with Parkinson's disease (PD) who experience fluctuations in the effectiveness of their levodopa medications. The results of this phase III clinical trial appear in the December 27, 2016, online edition of JAMA Neurology.

Levodopa is the gold standard medication for PD movement symptoms. But after several years of taking this drug, many people find that its effects wear off between doses. Drugs called COMT inhibitors can extend levodopa's benefits. But the two COMT inhibitors that are currently available have shortcomings: entacapone is safe but extends "on" time for less than an hour a day, and needs to be taken frequently; tolcapone (Tasmar®) has longer-lasting effects but can be toxic to the liver and require liver enzyme monitoring.

For the new study, an international team of researchers led by Andrew J. Lees, M.D., at the Reta Lila Weston Institute, University College London, London, compared the effects of treating wearing-off with two different doses of a newly developed COMT inhibitor. The double-blinded trial included 427 people with mild to moderate PD symptoms who experienced a minimum of 90 minutes of "off" time per day. Study participants were divided into three groups, taking either 25 mg opicapone, 50 mg opicapone or a placebo pill once a day for 14 or 15 weeks in addition to their standard PD medications. At the end of this period, the study was continued "open label" for another year, meaning that both medical staff and study participants were told who was getting what medication.

#### Results:

- Study participants who took 50 mg/day of opicapone reduced their "off" time by about an hour a day.
- The reduction in "off" time for the 50 mg/day group was sustained throughout the year of "open-label" use of the drug.
- The 25 mg/day dose of opicapone was no more effective than placebo.
- Although opicapone was generally well tolerated, side effects included dyskinesia, constipation and dry mouth.
- Participants had fewer incidents of severe diarrhea and liver toxicity with opicapone compared to other COMT inhibitors.

#### What Does It Mean?

This clinical trial found that a 50 mg dose of opicapone compares well, in terms of safety and effectiveness, with other COMT inhibitors that are currently available. Earlier clinical trials have reported similar results, and the drug was approved for use in Europe in July 2016.



The authors of an editorial that accompanies the research paper note that the once-a-day dosing may make opicapone easier and more practical for people with PD to use, and also allow doctors to fine-tune levodopa dosing more readily. They further recommend a "back to back" study comparing opicapone to other COMT inhibitors. The major limitation of the drug is that as expected, it increased the frequency of dyskinesia. The Parkinson's community urgently needs therapies that increase "on" time without worsening dyskinesia.

That said, if approved by the US Food and Drug Administration, opicapone will provide people with PD and their doctors a new option to consider for reducing "off" time.

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## Reminders of upcoming events as of Friday, March 10, 2017

### **REGULAR EVENTS:**

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 <sup>st</sup> Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 <sup>st</sup> Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Toby Feddis, 301-729-5569, lansgranny2007@yahoo.com Pam Dolly, 304-738-2196, pameladolly89@gmail.com
Winchester PD Support Group Monthly Meeting	2 <sup>nd</sup> Tuesday @ 11:00 AM Winchester Church of God, Winchester, VA	Cheryl Reames, 540-662-4632 winchesterparkinsons@gmail.com
Central PA PD Support Group Meeting	2 <sup>nd</sup> Wednesday @ 1:30 PM Health South Rehab Hospital, Mechanicsburg, PA	Dan Yother, 304-676-2053 oldred714@verizon.net
Hagerstown Parkinson's Support Group Caregivers' Breakfast	3 <sup>rd</sup> Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Frederick PD Support Group Monthly Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
Frederick County Parkinson's Early Onset or Newly Diagnosed Community Support Group	3 <sup>rd</sup> Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 bergstromdf@gmail.com
Cross Keys Parkinson's Support Group	3 <sup>rd</sup> Thursday @ 2:15 PM Cross Keys Village, New Oxford, PA	Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net
Chambersburg Parkinson's Support Group	Meets every TBD Meets at Physical Therapy Etc. 142 Franklin Farm Lane, Chambersburg, PA	Kathy Smith, 717-737-8320, Kathy.smith@embarqmail.com Jan Benedict, 717-263-5147

### **OTHER EVENTS:**

- Monday, March 20, 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, March 23, 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.
- Friday, March 24, 2017, 1:00 4:00 PM Bowling: Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Contact Dean Cook for more information at 304-268-1623 or <u>home2wv@yahoo.com</u>.
- Friday, March 24, 9 AM 12 PM Newly Diagnosed Parkinson's Disease Forum: St. Thomas Episcopal Church, Towson, MD.
  Contact: GiGi Gray at 410-955-6692 or ggray8@jhmi.edu.
- <u>Saturday, March 25, 2017, 10:00 AM 4:15 PM, Parkinson Foundation of the National Capital Area Symposium</u>, Falls Church, VA. To register for this event, call 703-734-1017 extension 1 or 301-844-6510 extension 1, Monday Friday during the hours

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of 9:00 am and 5:00 pm.

- <u>Thursday, April 6, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting</u>: <u>Sandra Mertz, Lunbeck, Neurogenic</u> Orthostatic Hypotension.<u></u>Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Tuesday, April 11, 2017, 10:00 AM, WCCA Caregiver Support Group meeting.</u> Topic: Dynamics of Family Caregiving and the roles that Family Member takes on. Speaker: Chis Fisher, Delegating RN at Right at Home In-Home Care and Assistance. Call 301-790-0275 ext. 221 for information.
- Monday, April 17, 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>Wednesday, April 26, 6PM 8:30PM Surgical Therapeutics for Parkinson's</u>: Deep Brain Stimulation and Duopa Information Session, St. Thomas Episcopal Church, Towson, MD. Contact: GiGi Gray at 410-955-6692 or ggray8@jhmi.edu.
- <u>Thursday, April 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.

-----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	Patients & Caregivers Breakout Sessions
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	TBD
September 7	Patients & Caregivers Breakout Sessions
October 5	Dr. Stephen Ryan, Physical Therapist
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