

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

December 2019

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

[Visit us on Facebook](#)

Volume 9, Issue 12

This Month's Meeting

December Meeting

There were **36** people at our November 7th support group meeting. Our speaker was Tarita Turner, a graduate of the Deaf Studies program at Towson University and an outreach coordinator for Maryland Relay/Telecommunications Access of MD. She explained Maryland Relay was established in 1991 to serve individuals who have difficulty using a standard telephone. Tarita described some of the solutions available to meet the needs of these disadvantaged individuals.

Bill Storms 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; **Ecile Shaw** is still recovering from her medical issues and was not able to attend the meeting.

Thanks to Carol Gaines, Judy and Sam Fiery and the other members who worked hard to set up the meeting and put things away after. Without that support, we would not be able to hold the kinds of meetings we do. I appreciate your efforts.

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, December 5, 2019, 11:45 AM

CHRISTMAS PARTY

Newsletter Highlights

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

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

An Article by Dean Cook ([Page 5](#))

Awards and Christmas Party ([Page 6](#))

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

Hagerstown Parkinson's Support Group Meetings in 2019

Dec 5 Christmas Party & Gift Exchange

Meetings in 2020

Jan 2, Amanda Distefano, Commission on Aging
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

SPOTLIGHT

**December 5th Meeting
is our
Christmas Party
See [Page 6](#)**



Hello Everyone:

Art, knowing how much I enjoy writing, has offered to include articles from me in the monthly newsletter. We have agreed on an arrangement whereby I will submit, on occasion, something I have written to be included in the Newsletter. Art and I will work to see what fits in the space he has available. It will be entirely up to him to decide what to use and when to use it.

My first offering is something I wrote to characterize my PD Trial experience with Dr. Alexander Pantelyat. You can read it on [Page 5](#) of this newsletter.

Dean Cook

The Hagerstown Parkinson's Support Group

Group Facilitator:

Art Guyer, 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 and Lunch

Our Caregivers' **Breakfasts** are on the 3rd Monday of every month. This month the breakfast is scheduled for **November 18th 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 **November 25th 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

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.

Christmas Party

December 5, 2019



See [Page 6](#) for Details

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 are working with Homewood to schedule similar sessions in 2020.

We 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 free lunch, crafts, discussions and presentations. Please help guarantee enough food is purchased by making a reservation.

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 November meeting date is the 21st due to the Holiday.

Accessible Home Health Care
"We Guarantee Compassionate Care"



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

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 November

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

So we can celebrate your 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 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.

Yearend Awards

Our yearend awards will be coming up in several months. Each year we vote on the Outstanding Person With Parkinson's Disease and the Outstanding Caregiver. It will be a little while until we actually vote. The awards are made in the following year then. BUT I thought I would get you thinking about the possibilities now. We have a lot of great people in our group that continually help support the group and each other. Those who have awarded in the past are not eligible for another award. We will have more in the following months



SEE [PAGE 6](#) FOR DETAILS

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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)

Few of us are prepared for the diagnosis of a serious illness like Parkinson's Disease. As the reality of the diagnosis begins to take hold, you quickly learn that health care providers and medical professionals will now be a part of your life. Dealing with doctors, pharmacists, and therapists, and new medical terminology, procedures, and tests can be a real challenge. Taking an active role in managing your health care will give you back some control over your illness. For starters:

- Selecting a good provider that you like and with whom you have a good rapport. A doctor that rushes you through an appointment does not meet that criteria. If your doctor doesn't treat you with respect, listen to you, or see you as a whole person, find one that does. Learn to stick up for yourself and be your own advocate.
- Learn as much as you can about PD. The APDA, Parkinson Foundation, and the MJF websites are some of the best places to look online for valid, helpful information. You must be careful getting information from websites that do not have the credentials to be considered "best in the business."
- Make certain you know your medications and what they are for, including non-prescription products.

This and That Thoughts on my Mind by Art Guyer:

I've been thinking about our members' awards coming up at the end of the year. We have a number of members who have been assisting the board members manage our meetings and other events. Whether it is our regular meeting, a picnic, or a breakfast or lunch, those individuals show up early and set up the event without prompting, and then help with the clean up afterwards. These are the individuals who are outstanding members that should be recognized for their service. Please turn in your nominations.

Take care..... Art

Four-State Alliance Support Group News:

Next 4SAPS Leader Board Meeting: November 9, 2019, 2019; Steve Silvius will be facilitating this meeting.

Chambersburg Parkinson's Support Group: The **group is no longer holding meetings**. Members of this group are welcome to attend the Hagerstown Parkinson's Support Group meetings.

Friends in Frederick PD Support Group: The next meeting of this support group will be on **Wednesday, November 20, 2019**, at 1:00 PM. Subject: - Acorda Therapeutics makers of Inbrija (inhaled Levodopa). Contact Janet or Steve Silvius at 301-831-5609 for directions and more information.

PD Support Group of Frederick: The next meeting of this support group will be **Saturday, November 16, 2019**, at 12:00 PM. Their speaker will be Dr. Liana Rosenthal, Movement Disorder Specialist, Johns Hopkins University. 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!

Six Ways to Make It Easier for Caregivers To Take A Break

DailyCaring.Com

The secret to surviving long term caregiving is to pace yourself and rest when you're tired. Being constantly exhausted and severely stressed causes serious health issues and decreases your capacity to care for someone else. But some caregivers resist the advice to take regular breaks even when they have access to help. That's because for some, getting help with caregiving can be more of an emotional decision than a rational one. Many caregivers feel guilty about stepping away, even for a short time, or feel uncomfortable bringing a stranger into the house. There can also be other roadblocks to getting caregiving help so you can take a break. Most often, those are the love one's denial that they need help, unhelpful family members, or financial issues.



1. Accept that you'll feel guilty. Guilt is a normal part of caregiving simply because you care – it's never going to disappear. Don't let this stop you from getting the caregiving help you need. Taking regular breaks is the best way to maintain your overall health and your ability to provide care. Besides, how good would you feel if you never took any breaks and your health declined to the point where you could no longer care for your loved one? It doesn't do them any good if you're not physically or mentally well enough to be their caregiver.
2. Don't ask your loved one for permission. This isn't a decision that your loved one gets to make. Many loved ones refuse outside help because they're uncomfortable with the idea. And someone with dementia doesn't have the cognitive ability to make a rational decision. When seniors refuse, they're not thinking of your needs and are often not considering their own true needs either. That's why you need to make the decision, regardless of how they feel about it. All that matters is that they're safe and well cared for when you're not there.
3. Start before you really need it (if possible). It may take a while to find the right person to help and for them to learn the caregiving routines. That's why it's helpful to find help before you really need it. When you're putting together a team of family, friends, and volunteers, it can be less stressful if you have some time to get the team in place and work out the details. To make the transition easier, you could have someone come and shadow you until they learn the ropes and can be left alone with your loved one. Or, you could have someone come for a short time in the beginning and gradually increase their time as everyone adjusts to the new situation.
4. Combine paid services with help from friends, family, and volunteers. Hiring caregiving help can be expensive. But even if the cost is high, maintaining or improving your health is worth it. Being open to different sources of help also lowers the cost of taking regular breaks. Ask family or friends for help and seek out volunteer programs that offer companionship services. Then supplement those hours with paid help as needed.
5. Check in to know that your loved one is well-cared-for. You might be afraid or nervous to leave your loved one with a stranger or a family member with limited experience. To give you greater peace of mind, use simple, discreet ways to keep an eye on them and make sure they're treating your loved one well. You could sometimes come back early as a surprise check-in to see what's been happening. Or while you're out, call occasionally to hear how things are going. Another good move is to ask the caregiver to take notes, so you'll know what happened while you were out.
6. Be creative when introducing the hired caregiver. Nobody wants to be told that they're getting a babysitter. If your loved one is very resistant to outside help, be sensitive and creative when introducing them to the household. A careful approach is especially important to prevent seniors with dementia from reacting with fear or anxiety. For example, you could introduce the person as your helper around the house and have them help you with meal prep, light housekeeping, and simple care tasks. After a few of these visits, it will seem normal that they're around and it will be easier for you to leave to "run errands." You could also position it as doing that person a favor. Perhaps you could say that this person is in need of extra income, so you're helping them out with a few hours of work here and there. If family or friends are helping, you could say that they wanted to visit and spend some time catching up. When they become regular visitors, you can start popping out to "run errands."

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Writings from Dean Cook

Many of you will recall that in February of 2018, I presented Dr. Liana Rosenthal with a framed poem I had written that tried to capture in a light-hearted way the clinical trial experience from the viewpoint of the participant. Several months ago, I was asked to participate in another study with Dr. Rosenthal and Dr. Alexander Pantelyat, whom I had never met. I found Dr. Pantelyat to be a delightful, funny, fascinating individual and explained to him that he, too, would probably end up being the subject of my unpredictable pen. The following is the result of that discussion, reproduced with his permission. I hope you enjoy it. He did.

When A. J. Calls

By Dean Cook, 2019

I got this message from A. J. Hall, "We need your help once again. Doctors Pantelyat and Rosenthal have a study to begin. They need your fluids just like before; they'll sap you 'til you're dry. In return, you'll get quite sore and a tuna fish on rye."

So I traveled ninety miles that day and sat in traffic stalled.
And truly wished I'd been away the afternoon she called.
On the road two hours or more, my bladder's about to burst,
And as I reached the restroom door someone got there first.

This day is going downhill fast; I could be home in bed.
But I said "Yes," when A. J. asked, and here I am instead.
For two days I'll be prodded, poked, tapped and jabbed to bits,
Pulled and hammered and barely wrapped in a gown that never fits.

Counting back from Donald, I'll be asked the Presidents,
And instead of saying Ronald, to be ornery, mention Pence.
Asked to study drawings and tell them what I see,
"A hippo and a rhino look just the same to me."

Draw the time on this clock; let's play some scratch and smell.
Lemonade or a dirty sock, I can never tell.
And Annie Thompson I feel your pain, but you really should have known,
Never walk down a Boston street especially when you're alone.

I'm here to see Dr. Pantelyat, though I can't pronounce his name.
They said they needed fluids, a lot, and that is why I came.
I Googled the guy before I arrived; his credentials really glow.
And confirming his patients are still alive is very nice to know.

Pantelyat plays the violin, he's a virtual Renaissance man.
And to pay for his Stradivarius, practices medicine when he can.
By day with a reflex hammer, he's a doctor duty bound,
But his fingers can't wait to caress that fiddle when the sun goes down.

Music is therapeutic, he teaches, takes our minds off pain,
Tingles those tiny neurons it reaches way down deep in the brain.
One minute you're crying, thinking you're dying, with nothing left to lose,
Then you are humming while someone is strumming, "Don't you step on my blue suede shoes."

Well, the two days are over and I'm heading west, hoping I've been of some use.
I'm a few dollars richer, I gave it my best, my fluids will soon reproduce.
I ask myself, in the whole scheme of things, "Have we made any progress at all?"
All I can say is that when the phone rings, if it's A. J., I'll take the call.



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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 Art Guyer by the end of our December 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 Disease: _____

Describe briefly why you recommend this individual for this award:

Name of Nominee who is a Caregiver: _____

Describe briefly why you recommend this individual for this award:

Holiday Party Thursday, December 5, 2019

Our December meeting will be our annual holiday party and we will not have a speaker. Come and enjoy the afternoon with your fellow members.

We hope to have some special entertainment, 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 hope to get a couple volunteers to arrange some games and to handle present distribution.

For more information, contact: Art Guyer.

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Reminders of upcoming events as of Thursday, November 07, 2019

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, cjressler4040@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 Silvius, 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, ex- cluding 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, November 18, 2019, 8:30 AM – 10:00 PM Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, November 21, 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, November 25, 2019, 11:30 AM – 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, December 5, 2019, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: **Christmas Party**
- Monday, December 16, 2019, 8:30 – 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, December 12, 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.

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- Monday, December 23, 2019, 11:30 AM – 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, January 2, 2020, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Amanda Distefano, Washington County Commission on Aging
- 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.
- 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.
- Thursday, 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.
- Thursday, 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.

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 our MAPS account. Mail donations to: MAPS Treasurer, Box 450, Brooklandville, MD 21022