Hagerstown, MD and the Four-State Area

## **Monthly Newsletter**

**June 2016** 

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

Volume 6, Issue 6

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Visit us on Facebook

#### This Month's Meeting

**June Meeting** 

#### **Local Support Group Contacts**

We had **60 people** at our May meeting, including 2 new members. It was a great turnout.

Our speaker was Elder Law Attorney Michael G. Day who presented an excellent outline of some of the issues the aging population is faced and how to deal with them. Mr. Day's contact information is:

The Law Offices of Michael G. Day and Associates 10715 Downsville Pike # 101 Hagerstown, MD 21740 Phone:(240) 329-4610

**Dave Fleming** won the \$10 gift certificate to the Western Sizzlin' Restaurant donated to the support group by Paul Romsburg and his family.

Thanks to **Mike Saterbak** for delivering our prayer.

#### YARD SALE RESULTS

The May 7<sup>th</sup> Yard Sale was a huge success. Thanks to Dean and Carol Cook for suggesting this event and for handling almost all of the details. See page 4 for photos taken during the event.



#### MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, June 2, 2016, 11:45 AM

We will be holding break-out discussion sessions in June.

#### **Newsletter Highlights**

Tips for Making Life Easier (Page 3)
Heads Up, Caregivers! (Page 3)
Parkinson Yard Sale Results (Page 4)
Blood Test for Parkinson's? (Page 5)
New Drug for Hallucinations (Page 6)
Getting Better Sleep (Page 6)
Detailed Event Listing (Pages 7 & 8)

#### **Future Meetings**

Jun 2, Patients & Caregivers Breakout Sessions

Jun 17, Picnic in the Park

Jul 7, Candice Valencia, Trainer and Senior Yoga Aug 4, Becky Dunlop, RN, BSN, Johns Hopkins Sep 1, Shelley Steiner, Hospice of Wash. County Sep 16, Picnic in the Park

Oct 6, Dr. Kelly Mills, Neurologist from JHU Nov 3, TBD

Dec 1 Patients & Caregivers Breakout Sessions December Meeting will be Christmas Party Too

PICNIC TIME AGAIN, SEE PAGE 2 FOR MORE DETAILS OR CONTACT ART.

Winchester Area Parkinson's Support Group Cheryl Reames, Facilitator, 540-662-4632 winchesterparkinsons@gmail.com Facebook.com/winchesterPDsupport

Cumberland Parkinson's Support Group Toby Feddis, 301-729-5569, ianasgranny@yahoo.com Pam Dolly, 304-738-2196, pamaladolly89@gmail.com

<u>Friends in Frederick Parkinson's Support Group</u> Janet Silvious, 301-831-5609, janet@fifpdsg.org or John Kraft, 301-845-6514, john@fifpdsg.org. www.fifpdsg.org

<u>Frederick Parkinson's Disease Early Onset or</u>
<u>Newly Diagnosed Community Support Group</u>
Deb Bergstrom, Facilitator, 301-712-5381,
bergstromdf@gmail.com

<u>Central PA PD Support Group - West Shore</u> (Mechanicsburg, PA) Dan Yother, 304-676-2053, oldred714@verizon.net

Gettysburg Parkinson's Disease Support Group Paula Chaplin, 717-337-4407, pchaplin@wellspan.org

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

Former members of the Chambersburg and Martinsburg support groups are welcome to attend the Hagerstown meetings and events.

Attend a
Support Group
Meeting

Parkinson's Events Calendar On-Line.

The Hagerstown Parkinson's Support Group

Group Facilitator: Art Guyer 22215 Troy Lane Hagerstown, MD 21742 240-625-2722 4Parkinsons@gmail.com The Hagerstown Parkinson's Support Group is supported in part by:



17567 York Road Hagerstown, MD Stop by for lunch or dinner to support them! Thanks to Paul Romsburg, his family, and staff of the Western Sizzlin for supporting our group.

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please contact the Group Facilitator, Art Guyer.

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## **June 2016**

## Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month. In April, Dave DeHaven, Peg Hayzlett, Ecile Shaw, Art Guyer, Mike Saterbak, Carol Gaines, Linda Embly, Barbara Harrell, and Frank McConnell met for breakfast.

This month the breakfast is scheduled for Monday, May 16th at 8:30 AM at the Hagerstown Family Diner. This restaurant is located at 431 Dual Highway near the Best Western Grand Venice Hotel. Contact Art if you need information or directions.

You are encouraged to participate if possible. It gives caregivers the opportunity to seek advice in a safe environment and it allows feedback for future meetings and activities. If you need transportation, let us know and we will take care of it.

### **Need Transportation?**

Remember, if you need transportation to our meetings or other events, please let us know.

If you would like a couple of hours of free time and we can take your spouse for a short day trip, we will be happy to try to work something out for you.

Give Art a call or send him an email.

### **Senior EXPO**

The Washington County CARES 2016 Senior & Caregiver EXPO takes place this year on Monday, May 23, 2016, 10 AM – 3 PM at the Robinwood Professional Center (Blue/Silver Entrance). We have been invited to participate with an information table at this event. So, I am looking for volunteers to help staff the table during that period. Call me at 240-625-2722 or email me at 4Parkinsons@gmail.com if you are able to help out.

#### **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 possibly getting members of the Hager-stown Parkinson's Support Group to contact businesses, offices, schools, churches, civic groups, HOAs, etc. in other geographical areas. So, we are looking for volunteers to help distribute materials.

You can contact Dean for information or volunteer to help at 304-268-1623 or by email at home2wv@yahoo.com.

### Picnic Time Again

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

Date: Friday, June 17, 2016

Time: 12 Noon

#### **RSVP REQUIRED or SIGN UP AT MEETING**

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

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

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

Call me at 240-625-2722 or email at <u>4Parkinsons@gmail.com</u> for more info.

#### Cards

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

#### **PD Group Bowling**

Our bowling group is growing slowly and we are having fun. We had a good turnout in April, but Doris and I could not make it. Come out and join us. You do not have to be a good bowler to get in the game. In fact, newbies are welcome.

We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes. We are scheduled to bowl on May 19 at 1:00 PM.

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

### Birthdays in April

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

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.



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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**: You can make many simple and inexpensive modifications to your home to make it more accessible. Here are some of the easiest changes you can make:

- Arrange furniture so there are clear walking paths throughout the house. Remove barriers such as racks and stools.
- Place furniture in strategic locations if you need to touch or hold onto it as you walk. Remove castors and wheels.
- Remove throw rugs, which cause many trips and falls.
- Increase lighting by using the highest wattage light bulbs recommended.
- Replace glass shower doors with a lightweight shower curtain for safety and convenience.
- Store daily-use products (towels, dishes, food, medications and cleaning supplies) between waist and eye level to avoid reaching and bending.

This and That .... Thoughts on my Mind by Art Guyer: 2017

As we look forward to 2017, I have planned a little change in the meeting structure based on feedback from the survey we conducted early this year. Next year we will have 3 breakout sessions so you will have more opportunity to discuss your issues and suggestions with each other. Also, the December 2017 meeting will be a Christmas party only and will not have any "educational" aspect. We will need some "new" volunteers to help plan and execute the party. That will leave 8 months in which we will schedule speakers. I have already filled 5 of those slots.

Speaking of the survey: Here are the results of the two questions I asked:

1. Would you like to see a third breakout session in 2017?

Yes = 9 No = 4

2. Would you like to have a party in December 2017 in lieu of a regular meeting?

Yes = 10 No = 3

A number of speaker suggestions were also made and I am taking those into consideration as I book 2017.

Take care..... Art

### **Heads Up, Caregivers:**

National Parkinson Foundation Guide for Caregivers

Management of a PD patient often extends beyond the care of a physician. It often falls into the hands of a caregiver who is a relative or friend. As a caregiver, there are many ways you can help.

- If the person you care for receives physical, occupational, or speech therapy, make certain the exercises recommended are done with regularity. For your loved one to maintain and maximize independence, safety and activities of daily living, be sure to encourage exercising, such as walking and swimming.
- Also make sure your charge eats a balanced diet and consumes enough to maintain proper weight. Make certain recommended vitamins are taken.
- If swallowing difficulties occur, your loved one needs soft foods and must take small bites. Some suggest chopping food in a food processor. If the patient eats slowly, an electric warming tray to keep food warm will minimize the need to rush.
- Learn the Heimlich maneuver in case of choking. Your doctor should be able to show you how this is done.

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### Hagerstown Parkinson's Support Group Yard Sale Report

The yard sale on Saturday, May 7<sup>th</sup> was successful beyond everyone's expectations! We netted \$1,960 as a result of cash donations and proceeds from the sale of donated goods. That is quite amazing. Thanks to all of you who donated so many things that sold so well throughout the day. We had customers there from an hour before the start time until we had begun to pack things away at closing time, about 2:00 PM.





We had a good team out there all day long and each and every one of them contributed to the success. Thanks go out to:

Dean and Carol Cook, Connie and John Hipp, Faith Mattia, Dave DeHaven, Frank and Vi McConnell, Carol Gaines, Jack Nazelrod II, Dave Fleming, Jay Stouffer, Ragan Shaw, Doris Guyer, and Dean and Carol Cook's family and friends.

We also owe a huge "thank you" to Paul Romsburg and his family for allowing us the use of the parking lot and the restroom facilities. The location could not have been better which also contributed to the success of the sale. And it did not rain one drop there!



And guess who was singing a Patsy Cline classic!

MORE PHOTOS AT: https://goo.gl/cdXeJL



Part of the hard-working team is pictured above, left to right: Carol Cook, Carol Gaines, Art Guyer, Faith Mattia, Doris Guyer, Frank McConnell, Vi McConnell, Dean Cook, John Hipp, Ragan Shaw, and Dave Pearson.

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#### How Close Are We to a Blood Test for Parkinson's?

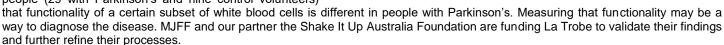
Michael J. Fox Foundation
Posted by Maggie McGuire Kuhl, April 25, 2016

A blood test to detect Parkinson's disease has been developed by Australian researchers, a breakthrough which will allow for earlier intervention and treatment of the debilitating condition. Currently there is no definitive test to diagnose Parkinson's disease and patients have to rely on a neurological exam, which can be problematic because results are often open to interpretation.

Last week Australia's <u>La Trobe University announced it had developed a blood test</u> to detect Parkinson's disease. While the team is making strides toward such a tool — and The Michael J. Fox Foundation is funding their further development — we're not there quite yet.

Currently Parkinson's disease is diagnosed through a clinical examination and elimination of other conditions that may cause similar symptoms (essential tremor, for example). An objective test for Parkinson's could help us diagnose earlier and more confidently, which may teach us more about this disease and help develop treatments to stop or slow progression.

The La Trobe researchers have shown in a small group of people (29 with Parkinson's and nine control volunteers)



In the meantime, MJFF is leading other initiatives to diagnose Parkinson's early and track its progression. The recently launched Systemic Synuclein Sampling Study (S4) measures the key Parkinson's protein alpha-synuclein around the body and the MJFF-led Alpha-synuclein Imaging Consortium is developing a tool to allow scientists to visualize alpha-synuclein in the brain.



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## **New Drug for Hallucinations and Delusions Coming Soon**

Parkinsons.org.UK, April 29, 2016

On April 29, 2016, the US Food and Drug Administration (FDA) approved pimavanserin - trade name Nuplazid - a new drug for treating hallucinations and delusions (sometimes called psychosis) in Parkinson's.

Hallucinations and Delusions in Parkinson's. Some people with Parkinson's may experience hallucinations or delusions. This means they may see, hear, smell or taste things that aren't there, or have thoughts and beliefs that aren't based on reality. There is hope that pimavanserin will be more effective than other drugs currently available.

Hallucinations and delusions are more common in people who have had Parkinson's for a long time, though they can affect both younger and older people. These symptoms may be caused partly by Parkinson's and partly by some Parkinson's medication. Medications for hallucinations and delusions are available but they often only have limited effect in Parkinson's.

Approval of this new drug provides one more tool for managing the symptoms of Parkinson's. And there is hope that pimavanserin could be more effective than other drugs that are currently available.

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#### Helping People with Parkinson's Get Better Sleep

Sleep Review, Published April 12, 2016

A study at The University of Western Australia (UWA) may offer hope in alleviating some of the memory and thinking skills problems associated with the debilitating movement disorder Parkinson's.

It comes as the Shake It Up Australia Foundation urges Australians to support World Parkinson's Day on April 11 to help raise awareness for those living with Parkinson's, along with money for vital research.

UWA PhD student Maria Pushpanathan says the research, which examined the links between poor sleep and cognition in people with Parkinson's and was published in <u>Sleep Medicine Reviews</u>, found that disturbed sleep had a profound effect on a patient's concentration, memory, and planning ability.

The research was undertaken as part of the ParkC project, a longitudinal study of thinking and motor symptoms in Parkinson's, which is a collaboration between Curtin University and UWA.

Pushpanathan and co-authors, associate professor Romola Bucks and ParkC director Dr Andrea Loftus, carried out a meta-analysis of all the available data from independent studies on night-time sleep problems and cognition in people with Parkinson's.

"While Parkinson's is classified as a movement disorder, it also affects thinking and memory skills, and causes sleep disruption," Pushpanathan says in a release. "It turns out that these sleep problems could be a significant factor leading to cognitive issues like poorer attention and memory loss. Having Parkinson's is tough, let alone if we add more cognitive problems due to poor sleep."

Pushpanathan says sleep disorders affect up to 98% of people with Parkinson's with the range of common disturbances including insomnia, sleep fragmentation, sleep-related breathing disorders, restless leg syndrome, REM sleep behavior, disorder and nightmares.

"While the number of studies that fit our criteria was relatively small and this field of research is in its infancy, it is the beginning of a new scientific adventure," Pushpanathan says. "What we have found could have major clinical implications by helping to raise awareness of how problematic sleep can have an enormous impact in Parkinson's."

"Our results also suggest that many types of sleep disorder, such as insomnia, and sleep-related breathing disorder, are not being identified or studied well in Parkinson's.

"We know that sufficient, good quality sleep is vital for physical and mental health, as well as for thinking and memory. Further research investigating the impact of these common sleep disorders in Parkinson's is desperately needed."

Pushpanathan says researchers now hope to look at how sleep disorder evolves as Parkinson's develops.

"Approximately 70,000 Australians are living with Parkinson's—imagine how life would be different if sleep was no longer a struggle, and memory loss could be delayed, reduced, or even prevented," she says.



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#### TV AND RADIO COVERAGE OF THE HAGERSTOWN PARKINSON'S SUPPORT GROUP

Dave Cook and Art Guyer did a live interview with Lou Scally on WJEJ on April 15<sup>th</sup> to promote the group and the yard sale. Art recently taped a "Contemporary Retirement" TV segment with Attorney Michael Day which will be <u>aired at 7:30 AM on May 29<sup>th</sup></u>. Art is also doing a live radio interview with Mr. Day on <u>Wednesday</u>, <u>June 1<sup>st</sup> at 9:30</u> on WJEJ, 1240 AM

If you cannot be 1240 AM on the radio, it is streamed on the internet at: http://tunein.com/radio/WJEJ-1240-s29805/.

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### Reminders of upcoming events as of Sunday, May 08, 2016

#### **REGULAR EVENTS:**

| Event  | Date, Time, Location  | Contact for Information                                    |
|--|---|--|
| Hagerstown Parkinson's Support Group Meeting   | 1 <sup>st</sup> Thursday @ 11:45 AM<br>Western Sizzlin Restaurant, Hagerstown , MD    | Art Guyer, 240-625-2722<br>4Parkinsons@gmail.com           |
| Cumberland PD Support Group Meeting  | 1 <sup>st</sup> Friday @ 4:00 PM<br>Grace Memorial Church, Cumberland , MD            | Tobby Feddis, 301-729-5569<br>Pam Dolly, 304-738-2196      |
| Winchester PD Support Group Monthly Meeting  | 2 <sup>nd</sup> Tuesday @ 11:00 AM<br>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<br>Health South Rehab Hospital, Mechanicsburg, PA | Dan Yother, 304-676-2053 oldred714@verizon.net             |
| Hagerstown Parkinson's Support Group<br>Caregivers' Breakfast                          | 3 <sup>rd</sup> Monday @ 8:30 AM<br>Hagerstown Family Diner, Hagerstown, MD           | Art Guyer, 240-625-2722<br>4Parkinsons@gmail.com           |
| Frederick PD Support Group Monthly Meeting   | 3 <sup>rd</sup> Wednesday @ 1:00 PM<br>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<br>WellSpan Adams Health Center, Gettysburg, PA   | Paula Chaplin, 717-337-4407 pchaplin@wellspan.org          |
| Frederick County Parkinson's Early Onset or Newly<br>Diagnosed Community Support Group | 3 <sup>rd</sup> Saturday<br>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<br>Cross Keys Village, New Oxford, PA              | Daune Wynn, 717-495-5671<br>wynn574@crosskeysvillage.net   |

#### **OTHER EVENTS:**

- Monday, May 16, 2016, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Wednesday, May 18, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series Subject: Vision (Dr. Dan Gold, DO.)
   St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD Contact: Phone 410-955-8795 Email rdunlop@jhmi.edu. Register
- Thursday, May 19, 2016, 1:00 PM 4:00 PM, Parkinson Bowling: Duckpins at the Southside Bowls at 17325 Virginia Avenue in Hagerstown, MD. For directions or carpooling, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com.
- Monday, May 23, 2016, 10 AM 3 PM, Washington County CARES 2016 Senior & Caregiver EXPO, Robinwood Professional Center (Blue/Silver Entrance). We will be having an information table at this event.
- <u>Thursday, May 26, 2016, Noon 1:00 PM Memory Café</u>: Free lunch and meeting at Ledo Pizza Restaurant located at 1423 Dual Highway, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

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- Thursday, June 2, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Breakout Discussion Sessions.
- Wednesday, June 15, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series
   Subject: Depression and Anxiety (Dr. Greg Pontone, MD)
   St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
   Contact: Phone 410-955-8795 Email rdunlop@jhmi.edu. Register
- <u>Friday, June 17, 2016, Noon 3:00 PM, HPSG Picnic. Bring a dish and a Bingo Prize.</u> For directions or information, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com. .
- Monday, June 20, 2016, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- <u>Thursday, June 23, 2016, Noon 1:00 PM Memory Café</u>: Free lunch and meeting at Ledo Pizza Restaurant located at 1423 Dual Highway, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

- <u>Thursday, July 7, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker is Candice Valencia, Personal</u> Trainer and Senior Yoga Instructor
- <u>Friday, July 15, 2016, 9:00 AM 12 Noon, Johns Hopkins PD Newly Diagnosed Forum</u>
   St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
   Contact: Phone 410-955-8795 Email rdunlop@jhmi.edu.
- Monday, July 18, 2016, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Wednesday, July 20, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series
  Subject: Advanced Treatments & Surgical Therapies (Dr. Kelly Mills, MD)
  St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
  Contact: Phone 410-955-8795 Email <a href="mailto:rdunlop@jhmi.edu">rdunlop@jhmi.edu</a>. Register.
- <u>Thursday, July 28, 2016, Noon 1:00 PM Memory Café</u>: Free lunch and meeting at Ledo Pizza Restaurant located at 1423 Dual Highway, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

#### 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 the account that MAPS has set up for our support group.

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