Hagerstown, MD and the Four-State Area

Monthly Newsletter

August 2016

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

Volume 6, Issue 8

Visit us on Facebook

August Meeting

Local Support Group Contacts

This Month's Meeting

There were **57 people** at our July meeting, including **5** new members.

Our speaker was Candice Valencia, a NSPA Certified personal trainer and a Certified Yogafit instructor with special certifications for the aging population. She talked about senior strength training and gentle yoga. She is an instructor at the Frederick, Brunswick, and Washington County Senior Centers.



Candice Valencia demonstrating exercises

Carol Cook won the \$10 gift certificate to the Western Sizzlin' Restaurant generously donated to the support group by Paul Romsburg and his family.

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

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, August 4, 2016, 11:45 AM

Our speaker will be Becky Dunlap RN, MS Instructor of Neurology, Associate Director, Johns Hopkins Parkinson's Disease and Movement Disorders Center

Newsletter Highlights

Tips for Making Life Easier (Page 3)
Heads Up, Caregivers! (Page 4)
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Picnic Report (Page 6)
Detailed Event Listing (Pages 7 & 8)

Future Meetings

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, Heinji Calara RN, Abbvie

Pharmaceuticals, with a Duopa Patient
Dec 1, Patients & Caregivers Breakout Sessions
December Meeting will be Christmas Party Too

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, lansgranny2007@yahoo.com Pam Dolly, 304-738-2196, pameladolly89@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

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

Central PA PD Support Group - West Shore (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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Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3rd Monday of every month. In June, **Peg** Hayzlett, Ecile Shaw, Art Guyer, Mike Saterbak, Carol Gaines, Dave DeHaven, Linda Embly, Frank McConnell, Gloria Rith, and Barbara Harrell met for breakfast. Ten members – a nice showing!

This month the breakfast is scheduled for Monday, July 18th 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.

ATTENTION:

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.

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.

Picnic Time Again

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

Dates: Friday, September 16, 2016

Time: 12 Noon

RSVP REQUESTED

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."

Pavilion #4 is at the end of the park road when you enter from Halfway Boulevard. Contact Art Guyer or Dave DeHaven if you need information or directions.

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 July.

PD Group Bowling

Our bowling group is growing slowly and we are having fun. We had a good turnout in June. 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 July 21 at 1:00 PM.

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

Birthdays in July

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

Safety and Emergency Provisions.

Put glow-in-the-dark stickers or tape on the handles of flashlights so you can find them easily if your electricity goes out. Or purchase specialty lights that plug into electrical outlets for charging and come on when the power is interrupted.

If you have diminished sensitivity to temperature, set your water heater's thermostat somewhere below 120F to avoid accidental scalding while bathing or washing. If you are uncomfortable doing this task yourself, ask someone else who can do it.

Keys, Doors, Doorways, and Doorknobs.

Replace regular doorknobs with lever handles or purchase a rubber lever that fits over any standard doorknob.

If a wheelchair is required, doorways can be widened or regular hinges can be replaced with offset hinges which allow the door to swing out and away from the doorway opening.

Buy adaptive key devices that fit on regular keys and give better leverage turning keys.

Keep duplicate full sets of keys in several places around the house in case you misplace a set. Try to put the keys you regularly use in one designated place

This and That Thoughts on my Mind by Art Guyer:



Doris and I want to thank everyone for their thoughtful cards and emails, warm phone calls, and sincere get well and birthday wishes. You all are a wonderful group of people and we consider all of you our friends.

Take care..... Art

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Heads Up, Caregivers: Coping Tips for Caregivers of Those with Parkinson's Disease

Reflexive Helping ... When Helping Hurts

Dr. Paul -- The Parkinsons Coach, 9881 Broken Land Pkwy, Columbia, MD

As Parkinson's Disease (PD) worsens, a person necessarily becomes more reliant on the family. Understandably, the family responds with an increased sensitivity to their loved one's needs.

However, problems arise when sensitivity morphs into a reflexive response to those needs. When helping another becomes a reflex, it is not always serving the best interests of the PWP or the partner.

There is no greater assault on a person's dignity and sense of worth than the frustration of struggling to do things that were once a natural part of daily life. Personal dignity takes a hit when that person has to ask for help but it can be absolutely battered when a loved one swoops in with assistance because the struggle is difficult for them to watch.



It is human nature to respond to a loved one in need. However, it is also human nature to become less likely to do tedious or difficult things when the act of trying seems to distress others. "Here, I'll do it" or "I can do it faster" can sound a lot like "You can't do it." It doesn't take long to fall into the habit of letting others soothe their distress through well-meaning action on your behalf.

Dependence can become the unintended consequence of reflexive helping. No partner wants to make things worse. Here are a couple of things you might want to try to master your reflex:

- Determine if the person can do an act without help, even if takes a bit of time and would be easier for you to do. If the answer is yes, give them the opportunity.
- If you are becoming angry or resentful, sit down with the PWP and discuss it. Agree on what you will do and what the person with PD will do.
- Learn to say no when you need to. It is not necessary for you to act upon every request unless there is a real risk for harm.
- If you are prone to feeling guilty, call a friend or someone from your support network.

When it comes to living with a person with PD, you simply cannot do it all. If you forget this simple fact, your reflex to help is causing dependence for your partner and very likely resentment in you.

Breath Strip Could Treat PD

Approximately three dozen researchers nationally are investigating a medication that works like a breath strip and has been shown to quickly control off-episode PD symptoms. If their research pans out, and the FDA gives its approval, the treatment could be on the market as early as 2017.

People with Parkinson's usually take three or four daily doses of levodopa, an oral medication that is converted to dopamine in the brain. But sometimes, as the disease progresses, the drug becomes less effective, and doesn't last from dose to dose. A shorter-lasting medication called apomorphine can serve as a bridge between doses. But it is only available in an injection.

The new treatment being explored would deliver apomorphine through a thin film not unlike a breath strip that patients would place under the tongue. Earlier studies show it helps control symptoms in most patients.

Researchers are now involved in a Phase 3 study. According to published data, there is an onset time of 24 minutes which may be longer than what the average Parkinson patient would hope for.

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Swallowing and Parkinson's Disease

Michelle Ciucci, November 05, 2013 (Thanks to Chuck Bihun for contributing this reference)

This guest post comes from Michelle Ciucci, PhD, CCC-SLP, an Assistant Professor at the University of Wisconsin and a National Foundation of Swallowing Disorders (NFOSD) board member. NFOSD is a 501(c)(3) nonprofit organization that seeks to improve the quality of life of those suffering from swallowing disorders (dysphagia). By enhancing direct patient support, education, research and raising public, professional and governmental awareness, NFOSD's mission is to prevent swallowing disorders and advance their treatment. NFOSD unites people with swallowing disorders with qualified specialists and support groups, increases awareness about swallowing disorders and provides valuable resources for therapists and their patients. NFOSD is also helping fund stem cell research to improve disordered lingual function that disrupts swallowing function.

Fast facts:

- Swallowing difficulty can occur at any stage of Parkinson's disease (PD).
- Evaluation and treatment of swallowing disorders are performed by a speech language pathologist.
- Swallowing disorders are treatable.
- The leading cause of death in Parkinson's is aspiration pneumonia due to swallowing disorders.

Difficulty swallowing, called dysphagia, can happen at any stage of Parkinson disease. Signs and symptoms can range from mild to severe and may include: difficulty swallowing certain foods or liquids, coughing or throat clearing during or after eating/drinking, and feeling as if food is getting stuck. As the disease progresses, swallowing can become severely compromised and food/liquid can get into the lungs, causing aspiration pneumonia. Aspiration pneumonia is the leading cause of death in PD.

It is important to note any changes to swallowing, because there is opportunity to intervene early and preserve both health and quality of life. Swallowing disorders are managed by the medical team with a speech-language pathologist and physician. Evaluation typically involves an interview, a physical examination of the head and neck, trials with food/liquid and if indicated, an instrumented examination, either with a moving x-ray, called videofluoroscopy (also known as a modified barium swallow study) or by visualizing the throat with a scope (called endoscopy).

Treatment is specific to the nature of the swallowing problem, but can involve strategies to help food or liquid go down safely (swallowing hard, holding breath while swallowing, tucking the chin while swallowing), diet changes (thickening liquids, making foods softer), exercises, or a combination of these. In some cases, alternatives to oral feeding, such as a feeding tube, are indicated. However, just because you have a swallowing problem, it does not mean that you will need a feeding tube.

Because Parkinson disease is progressive, swallowing abilities can change over time, underscoring the need for early intervention and frequent follow-up. Sometimes the signs of a swallowing disorder can be subtle, so it is important to be vigilant. If you think you have difficulty swallowing, ask your physician to refer you to a speech language pathologist for a swallowing evaluation.

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ATTENTION:

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.

I know a few of you already provide this service and I greatly appreciate your stepping up to help other members. That is what a support group is about!

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September Picnic a Success



Members of the Hagerstown Parkinson's Support Group enjoyed a beautiful day for their June 17, 2016, picnic. The sky was clear, the temperature moderated by a light breeze. The rain that forecasters had been predicting came through the night before leaving a perfect, dry day for the group. Forty-five members and family met at the Martin L. Snook Memorial Park in Hagerstown, MD. The crowd enjoyed lively conversation, good food including ACT fried chicken, some music, games, and bingo. Everyone won at least one bingo prize and **John Hipp** won the "When Was It Invented" contest by a large margin. **Dave DeHaven** contributed a dozen potted flower plants that were given away by drawings and by bingo.

The group's facilitator, **Art Guyer**, welcomed the group and reminded them we started having our picnics in 2012 and have had two a year since then. He emphasized that the success of the group is due to the willingness of its members to participate. He thanked the attendees for the support to the group's success and for their support to each other. He also thanked the members who came early and stayed late for set up and clean up.

Photos were taken by **Talia Valencia** who also brought "Blueberry" the bunny rabbit along and dubbed him the new mascot. Everyone loved "Blueberry" and he loved the attention. He also posed for some good photos.





See Page 2 for information on our September picnic.

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Reminders of upcoming events as of Sunday, July 10, 2016

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 Health South Rehab Hospital, Mechanicsburg, PA	Dan Yother, 304-676-2053 oldred714@verizon.net
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

OTHER EVENTS:

- <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 ggray8@jhmi.edu
- Monday, July 18, 2016, 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.
- 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 ggray8@jhmi.edu. Register.
- Thursday, July 21, 2016, 1:00 3:00 PM, Bowling. Southside Bowls, Virginia Avenue. For directions or information, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com
- Thursday, July 28, 2016, Noon 1:00 PM Memory Café: 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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- Monday, August 15, 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, August 17, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series
 Subject: Genetics (Valina Dawson, PHD and Weiyu Mu. SCM, CGC)
 St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
 Contact: Phone 410-955-8795 Email ggray8@jhmi.edu. Register.
- Thursday, August 25, 2016, Noon 1:00 PM Memory Café: 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@ahcqlobal.com.
- Thursday, September 1, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker is Shelley Steiner, Hospice of Washington County.
- Friday, September 16, 2016, Noon 3:00 PM, HPSG Picnic. Bring a dish and a Bingo Prize. For directions or information, contact Dave DeHaven at 301-582-2815 or by email at haddehaven@aol.com.
- Monday, September 19, 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, September 21, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series
 Subject: Legal Planning (Jason Frank, CELA)
 St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
 Contact: Phone 410-955-8795 Email ggray8@jhmi.edu. Register.
- Thursday, September 22, 2016, Noon 1:00 PM Memory Café: 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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- <u>Saturday, October 15, 2016, 7:00 AM, Pacing 4 Parkinson's, M&T Bank Ravens Stadium, Baltimore, MD.</u> Contact: Phone 410-955-8795 Email <u>rdunlop@jhmi.edu</u>. <u>www.pacing4parkinsons.org</u>.

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