Hagerstown, MD and the Four-State Area

Monthly Newsletter

August 2019

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

Volume 9, Issue 8

This Month's Meeting

August Meeting

There were **43** attendees at our July 11th support group meeting. Our speaker was **Attorney Michael Day** who spoke on Elder Care Law. Mr. Day spoke on how to avoid loss of assets if faced with long-term stays in nursing homes.

Phyllis Davis 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. She is at home now and seems to be improving. She says she misses all of you.

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, August 1, 2019, 11:45 AM Featuring

David Kukor Accessible Home Care

Newsletter Highlights

Tips for Making Life Easier (Page 3)
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Picnic Report (Page 5)
Gut Bacteria (Page 6)
Detailed Event Listing (Pages 7 & 8)

Hagerstown Parkinson's Support Group Meetings in 2019

Aug 1, David Kukor, Accessible Home Care Sep 5, Member Discussion

Sep 20, Picnic!

Oct 3, Marissa Yoes, Parkinson Voice Project Nov 7, Tarita Turner, Hamilton Relay Comm. Dec 5 Christmas Party & Gift Exchange

Meetings in 2020

Jan 2, Amanda Distefano, Commission on Aging

Feb 6, Kristen Francis, TBD

Mar 5, Jacinta Handon, Adamas, with a Doctor Apr 2, Katy Kobel, FOX Rehab, LSVT/BIG

SPOTLIGHT

New Meeting! We are beginning a <u>Caregiver's Lunch on the 4th Monday of every month at 11:30 AM</u> at the Hagerstown Family Diner on the Dual Highway. We are still doing the Caregiver's Breakfast on the 3rd Monday as usual – same time, same place. Come out to one or both of these and join the group.

Dementia

Dementia refers to a syndrome in which patients have problems in more than one cognitive domain, and the cognitive problems significantly impair everyday life functioning.

About 40% of Parkinson's Disease patients develop dementia.

Dementia in Parkinson's Disease typically develops many years after the initial onset of Parkinson's Disease and is more common with advanced disease.

When dementia develops before or at the same time as Parkinson's Disease motor symptoms, patients are often given the diagnosis of dementia with Lewy bodies.

Many physicians and researchers, however, consider Parkinson's Disease dementia and dementia with Lewy bodies to represent related disorders and fall under an umbrella term of "Lewy body disorders."

American Parkinson's Disease Association

The Hagerstown Parkinson's Support Group

Group Facilitator:

Art Guyer, 240-625-2722 <u>4Parkinsons@gmail.com</u> 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 **Monday**, **July 15**th **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. The date will be **July** 22nd at 11:30. It will be at the *Hagerstown Family Diner* also. Contact Art if you need information or directions.

Picnic

Friday, September 20, 2019 11:30 AM Marty Snook Mem. Park, Pav. #4 Hagerstown, MD

- Bring a covered dish or dessert; there will be fried chicken.
- The cost of the chicken and the fee for rental of the pavilion will be prorated to those attending.
- There will be free bingo for all! Everyone should bring one or more wrapped, inexpensive "prizes" for bingo winners.

Contact Art if you are coming.

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.

Senior Homes Activities

We are scheduled to hold PD Round Tables at **Homewood at Williamsport** on the following Wednesdays:

- July 17, 2019
- October 16, 2019

We had our last one on May 15th; Judy Fiery and Art Guyer led the session.

We hope to continue these presentations with other senior facilities in the Hager-stown 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. This month's meeting is July 25th. Contact Dave Kukor at 301-639-3166 or email at dkukor@ahcglobal.com for reservations (required) and information.



"We Guarantee Compassionate Care"

Accessible Home Health Care Owners Carmine and Dave Kukor are the speakers at our August 1st meeting.

Don't miss this presentation!

PD Group Bowling

Southside Bowl will provide lanes for our group at 1:00 PM on the fourth Thursday of each month. Please join us at 17325 Virginia Avenue, Hagerstown. Games are priced at \$2; bowling shoes are free. The date this month is July 25th.



Bowlers in June: Jan Silvious, Art Guyer, Steve Silvious, and Edie Johnson

Birthdays in July

Happy Birthday to members who have birthdays this month. We will announce your names and sing happy birthday to you at our meeting in August.

So we can celebrate <u>your</u> birthday at our meetings, contact Art who keeps a master schedule for the group. No years required, just month and day!

In The Hospital?

If you or your spouse, or a member you know is not doing well and/or is in the hospital, please let us know. We like to visit our friends when possible. Carol Gaines 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.

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Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

Empowering Yourself - Mobility Devices

- Take a cane to help stabilize your walking when visiting unfamiliar places. People will usually try to be more careful not to bump into you when you use a cane.
- If you use a cane and must go out in icy weather, screw into the bottom of your cane a removable ice gripper tip.
- If you use a cane in winter and have difficulty gripping the cane handle while wearing mittens or gloves, knit or crochet a small sleeve to fit snugly over the handle. The woolen glove and the woolen cover will work together to keep the handle from slipping.
- Use a walking stick that resembles a shepherd's staff if you have trouble walking with the traditional cane but need support when you walk. Your elbow is bent at a 90-degree angle and the staff is in front of you. The staff also helps you stand up straighter when your back muscles are weak.
- Consider using a wheeled walker. Walker models are available with wheels and brakes, a seat in the middle for you to rest, and a basket above the wheels to put loose items in.
- Adapt a traditional walker for easier use: put 3-inch wheels on the front legs and tennis balls on the back legs of the walker, especially if you have a thick or looped carpet.
- The Phil-E-Slide System is made of ultra-low friction material that improves comfort and independent ce by enabling a person to transfer with significan tlyless discomfort and by giving him the ability to assist in the transfer process. More information is at: https://phil-e-slide-uk.com/products.php.

This and That Thoughts on my Mind by Art Guyer:

I've been think about what a nice picnic we had last month. The weather and the food were great and **Carol Gaines** did a great job at calling bingo. In memory of **Paul Embly**, the Embly family paid for the fried chicken and we had a moment of silence for Paul. We have another picnic coming up in September so please sign up for the event – you will enjoy it. For more information and photos, see <u>page 5</u>.

Take care Art

Four-State Alliance Support Group News:

Next 4SAPS Leader Board Meeting: July 13, 2019.

Chambersburg Parkinson's Support Group: The group will hold its next meeting on Friday, August 16th, their speaker will be Dr. Subramanian. The contact for this group is Kathy Smith, 717-377-8320. Phone her for more information.

Friends in Frederick PD Support Group: The next meeting of this support group will be on Wednesday, September 18th, 2019, at 1:00 PM. Speaker: Mary Collins – Dept. of Senior Services Caregiver Program. Contact Janet or Steve Silvious at 301-831-5609 for directions and more information.

PD Support Group of Frederick: The next meeting of this support group will be **Saturday, July 20, 2019**, at 12:00 PM. Their speaker will be **Dr. Cayer - Nutrition**. They meet at the YMCA at 1000 N. Market Street in Frederick. 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!

How Caregiver Support Groups Can Help

DailyCare.Com

One of the primary benefits of caregiver support groups is that they provide much-needed *social* support. This is especially important when family and friends aren't supportive.

Support group members validate each other's experiences. It's a relief to know that what you're going through is normal and that you're not the only one with these feelings – <u>negative or positive</u>.

Support groups are also a great place to ask for advice, find out about useful resources, or vent frustrations. You won't have to worry about judgement or confusion from non-caregivers since everyone is going through similar struggles.

8 Benefits of Caregiver Support Groups

Decades of research and anecdotal evidence show that there are clear benefits to participating in caregiver support groups.

Here are the 8 top benefits:

- · Feeling less lonely, isolated or judged
- · Reducing depression, anxiety, or distress
- Gaining a sense of empowerment and control
- Getting advice or information about practical solutions or treatment options
- Improving or learning healthy coping skills
- Getting a better understanding of what to expect in the future
- Improving caregiving skills and giving better quality of life to your loved one
- Learning about ways to keep your loved one at home longer

That is why the board of the Hagerstown Parkinson's Support Group began our Caregiver's Breakfasts several years ago. While not a full-blown support group with speakers, etc., it provides the benefits listed here. We now have added a Caregiver's Lunch to our agendas. Our breakfasts are on the third Monday of every month at 8:30 AM at the Hagerstown Family Diner on the Dual Highway.

On June 24th, we held our first Caregiver's Lunch at the same location at 11:30 AM. We felt the lunch would be beneficial for those who wanted to participate but were not able to get out of the house that early in the day. There were 6 people at the lunch, and they decided we would continue meeting on the 4th Monday of every month at 11:30 AM at the Hagerstown Family Diner.

I encourage all caregivers to join our breakfast or lunch (or both) group. You will find it is easy to discuss issues and solutions and whatever else anyone wants to talk about.



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Hagerstown Parkinson's Support Group Picnic on June 21, 2019.

The Hagerstown Parkinson's Support Group held its summer picnic on June 21, 2019. Thirty-nine persons associated with Parkinson's Disease enjoyed the day at Martin "Marty" L. Snook Memorial Park. It was a beautiful day for a picnic in the park. The group dined on fried chicken from AC&T accompanied by a variety of dishes and desserts provided by the participants. It was a good day, meeting some new people and reuniting with some old friends. The host, Art Guyer, recognized the absence of Paul Embly who died recently. There were also drawings for a \$10 gift certificate to the Western Sizzlin' Restaurant, a bag of chocolate, and several other small prizes. Board Member Carol Gaines called bingo for the group, giving away about 40 wrapped prizes brought by the members.

Attending the picnic were: Art Guyer, Mike Saterbak, Harry and Phyllis Davis, Bill and Marquita Storms, Jay and Betty Stouffer, Bonnie Embly, Linda Embly, Belinda Neff and son Dylan, Marie Fogarty, Talia Valencia along with our *mascot Blueberry the Bunny*, Edie Johnston, Cindy and Gary Swales, Charles and Bonnie Emery, Bill and Shirley Whetzel, Judy

and Sam Fiery, Karen and Robert Calandrelle, Carolyn and Holly McKee, Judy Franz, Carol Gaines, Kathryn Koenig, Shane Flaherty, Peter Lukacs, Amy and Karen Kelley, Susan Drury, and Bill and Ruby Wilhide.

Also attending were Caroline Morse and Makea Luzader from WDVM-TV who recorded video for Friday night's newscast, interviewing several of the attendees. That newscast is available at: https://bit.ly/31WqxTU

The Hagerstown Parkinson's Support Group will hold another picnic on September 20th at the same place.

Selfie by Talia Valencia (Art's Granddaughter) and the support group mascot, Blueberry the Bunny

Photos by Talia



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Gut-Dwelling Bacterium Consumes Parkinson's Drug

June 25th, 2019 by Dr. Francis Collins

Scientists continue to uncover the many fascinating ways in which the trillions of microbes that inhabit the human body influence our health. Now comes yet another surprising discovery: a medicine-eating bacterium residing in the human gut that may affect how well someone responds to the most commonly prescribed drug for Parkinson's disease.

There have been previous hints that gut microbes might influence the effectiveness of levodopa (L-dopa), which helps to ease the stiffness, rigidity, and slowness of movement associated with Parkinson's disease. Now, in findings published in Science, an NIH-funded team has identified a specific, gut-dwelling bacterium that consumes L-dopa [1]. The scientists have also identified the bacterial genes and enzymes involved in the process.

For the 10 million people in the world now living with this neurodegenerative disorder, and for those who've gone before them, L-dopa has been for the last 50 years the mainstay of treatment to help alleviate those motor symptoms. The drug is a precursor of dopamine, and, unlike dopamine, it has the advantage of crossing the blood-brain barrier. Once inside the brain, an enzyme called DOPA decarboxylase converts L-dopa to dopamine.

Unfortunately, only a small fraction of L-dopa ever reaches the brain, contributing to big differences in the drug's efficacy from person to person. Since the 1970s, researchers have suspected that these differences could be traced, in part, to microbes in the gut breaking down L-dopa before it gets to the brain.

To take a closer look in the new study, Vayu Maini Rekdal and Emily Balskus, Harvard University, Cambridge, MA, turned to data from the NIH-supported Human Microbiome Project (HMP). The project used DNA sequencing to identify and characterize the diverse collection of microbes that populate the healthy human body.

The researchers sifted through the HMP database for bacterial DNA sequences that appeared to encode an enzyme capable of converting L-dopa to dopamine. They found what they were looking for in a bacterial group known as Enterococcus, which often inhabits the human gastrointestinal tract.

Next, they tested the ability of seven representative Enterococcus strains to transform L-dopa. Only one fit the bill: a bacterium called Enterococcus faecalis, which commonly resides in a healthy gut microbiome. In their tests, this bacterium avidly consumed all the L-dopa, using its own version of a decarboxylase enzyme. When a specific gene in its genome was inactivated, E. faecalis stopped breaking down L-dopa. These studies also revealed variability among human microbiome samples. In seven stool samples, the microbes tested didn't consume L-dopa at all. But in 12 other samples, microbes consumed 25 to 98 percent of the L-dopa!

The researchers went on to find a strong association between the degree of L-dopa consumption and the abundance of E. faecalis in a particular microbiome sample. They also showed that adding E. faecalis to a sample that couldn't consume L-dopa transformed it into one that could.

So how can this information be used to help people with Parkinson's disease? Answers are already appearing. The researchers have found a small molecule that prevents the E. faecalis decarboxylase from modifying L-dopa—without harming the microbe and possibly destabilizing an otherwise healthy gut microbiome.

The finding suggests that the human gut microbiome might hold a key to predicting how well people with Parkinson's disease will respond to L-dopa, and ultimately improving treatment outcomes. The finding also serves to remind us just how much the microbiome still has to tell us about human health and well-being.



Date Time Location

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Event

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Contact for Information

Reminders of upcoming events as of Thursday, July 11, 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, cjcressler4040@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 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
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 Support Group	3 rd Thursday @ 1:00 - 3:15 PM Cross Keys Village, New Oxford, PA	Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net
Chambersburg Parkinson's Support Group	3 rd Friday, every 2 months (Even Months) @ 4 PM at Physical Therapy Etc. 142 Franklin Farm Lane, Chambersburg, PA	Kathy Smith, 717-377-8320, Kathy.smith@embarqmail.com
Carroll County Parkinson's Support Group	2 nd Wednesday, every 2 months (Even Months, excluding 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, July 15, 2019, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Monday, July 22, 2019, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, July 25, 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, July 25, 2019, 1:00 PM 3:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown.

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- Thursday, August 1, 2019, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be David Kukor, Accessible Home Care.
- Monday, August 19, 2019, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, August 22, 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, August 22, 2019, 1:00 PM 3:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown.
- Monday, August 26, 2019, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, September 5, 2019, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be David Kukor, Accessible Home Care.
- Monday, September 16, 2019, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Friday, September 20, 2019, 11:30 AM 3:00 PM, HPSG Picnic. Bring a dish and enjoy AC&T fried chicken. Marty Snook Mem. Park, Pav. #4.
- Monday, September 23, 2019, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, September 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 dku-kor@ahcqlobal.com.
- Thursday, September 26, 2019, 1:00 PM 3:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown. .
- Thursday, October 3, 2019, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Marissa Yoes, Parkinson Voice Project.
- Monday, October 21, 2019, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, October 24, 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, October 24, 2019, 1:00 PM 3:00 PM, Bowling. Southside Bowl, 17325 Virginia Avenue, Hagerstown.
- Monday, October 28, 2019, 11:30 AM 2:00 PM Caregivers' Lunch: Hagerstown Family Diner, Hagerstown, MD.
- Thursday, November 7, 2019, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker will be Tarita Turner, Hamilton Relay Commission

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