

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

December 2016

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

Volume 6, Issue 12

This Month's Meeting

December Meeting

Local Support Group Contacts

There were 67 people at our November meeting, including the speakers, and a guest, Dory Kennedy, from *Right at Home*,

In addition to the guests, we had 4 new first-time attendees, making a very nice attendance.

Our speakers were Heinji Calara a nurse educator from AbbVie who spoke about Duopa, along with a patient, John Nicodemus, who uses the pump and drug system. Mr. Calara did an excellent job of explaining the system, how it works, the benefits and the drawbacks. Mr. Nicodemus was a part of the initial clinical trials and has been using the system for about 8 years. He discussed his experiences and the results he achieved.

For more information on Duopa, see the article on [Page 6](#).

Jack Nazelrod won the \$10 gift certificate donated to the group by the owners of the Western Sizzlin' Restaurant.

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

Please keep **Sandy Phillip's** family in your prayers. Don Phillips passed away on Friday, October 14, 2016, at home. Don will be missed by all of us.

Also, **Harry Davis** fell and broke his hip. He and Phyllis need your good thoughts and prayers as well.

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the
Western Sizzlin Steakhouse
17567 York Road, Hagerstown, MD

Thursday, December 1, 2016, 11:45 AM

**Open Discussions and
Christmas Party and Gift Exchange**
Bring a wrapped gift costing no more than \$10

Newsletter Highlights

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

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

Outstanding Members - 2016 ([Page 4](#))

New Dyskinesia Drug ([Page 5](#))

Duopa Enteral Suspension ([Page 6](#))

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

Future Meetings

Dec 1, Open Discussion Session

December Meeting will be Christmas Party
Bring wrapped gift costing no more than \$10

2017

Jan 5, Patients & Caregivers Breakout Sessions

Feb 2, Daniel Quirk, DPT, Fox Rehabilitation

Mar 2, Jaclyn Garrish, Speech-Language Path.

Apr 6, Sandra Mertz, Neuro. Ortho. Hypotension

May 4, Patients & Caregivers Breakout Sessions

Winchester Area Parkinson's Support Group
Cheryl Reames, Facilitator, 540-662-4632
winchesterparkinsons@gmail.com
[Facebook.com/winchesterPDsupport](https://www.facebook.com/winchesterPDsupport)

Cumberland Parkinson's Support Group
Toby Feddis, 301-729-5569,
lansgranny2007@yahoo.com
Pam Dolly, 304-738-2196,
pameladolly89@gmail.com

Friends in Frederick Parkinson's Support Group
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@wellspring.org

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

**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.

This month the breakfast is scheduled for **Monday, November 21st 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?



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

If you no longer drive or have limited your driving and would be interested in getting a ride to one of our activities from another member, send me a note or call me and I will post a list. I am hoping there will be other members happy to help out and offer transportation.

Thanks to those good people who are already providing transportation to others on a regular basis now. You make this group special.

Ride Needed List:

Larry Pereschuk
3820 Trego Mountain Rd
Keedysville, MD (301-432-2722)

Glenda Austin
1625 Woodlands Run
Hagerstown, MD (301-791-1361)

Cancellation Due to Weather

Our **weather cancellation policy** is based on the Washington County School System. **If the Washington County Schools announce they are closed for the entire day, then we will not have our regular monthly meeting. Also, I will send an email out by mid-morning if it is to be cancelled; those without email should listen to the TV and Radio for the school announcements.**



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.



Operation Christmas Child Donations

Thanks again for your generous donations for Operation Christmas Child. If you'd still like to donate items for boxes or filled shoeboxes you may bring them to the December meeting.

A. Candice Valencia

PD Group Bowling

We will not be bowling the rest of the calendar year due to holidays and other conflicts. After the first of the year we will resume if we get enough participants.

You do not have to be a good bowler to get in the game. In fact, newbies are welcome.

We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes.

Birthdays in November

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



So we can celebrate your 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: The Bathroom

- Crisscross two pieces of adhesive tape over the bolt on the bathroom door. Adults who are confused or have trouble operating a doorknob will not be able to lock themselves in the bathroom.
- If the bathroom doorway is too narrow to manage, remove the door. Replace it with a tension rod and a shower curtain liner. More clearance is helpful not just for wheelchair users, but also for those who use a walker or require assistance. I have done this for a walk-in closet.
- Purchase a telescoping mirror that either clamps to the side wall of the vanity or sits on top of the vanity counter. They feature adjustable, swivel –type necks that can be moved to various positions easily.
- Consider buying a removable showerhead on a flexible, hand-held extension hose. They make showering much easier, especially if you're sitting on a bench or shower chair. If it is too slippery to use safely, wind some rubber bands around the handle.
- Purchase an appropriate bench or chair for the tub or shower so you can sit to wash, reducing the fall risk.
- Purchase an adjustable, portable toilet seat to increase the height and make it easier to get on and off the toilet. Some models can be used as a bedside toilet during the night if necessary.

This and That Thoughts on my Mind by Art Guyer:

How can any of us help but think about those in our group who have passed away this year, and years past. Just this year alone we lost Doris Fearnow, Rodger Shuman, Austin Gladhill, Fred Lockard, Connie Hipp and Don Phillips. They all left family and friends behind but they are all at rest now. Please keep them all in your thoughts and prayers.

We urge the family members who survive to continue to attend our support group meetings and other activities. Some of you have already told me you plan to do so. Join us when you are ready. You will be a support to others in the group.

Take care..... Art

ODDS and ENDS

High-End Recliner/Lift Chair and Wheel Chair for Sale.

If interested, call Sandy Phillips for prices and descriptions at 240-420-3696.

Friends in Frederick Parkinson's Support Group Looking for practical solutions for problems facing PD patients. They are going to publish a book of pointers based on input from people associated with PD. Call Janet Silvius at: 301-831-5609.

Do you feel you are missing out on the conversation? Connect with Maryland Relay: Dial 7-1-7

Multiple Calling Options, Captioned Telephone, or Assistive Equipment. 443-453-5970 or 800-552-7724

Potential Chambersburg PD Exercise Class and Support Group

Kathy Smith has been seeing a physical therapist in Chambersburg, called "Physical Therapy etc." They are in the process of starting an exercise class for PD, most likely two times a week! They also are discussing the possibility of hosting a PD Support Group at their facility. Those of you in that area may be interested in contacting them; their phone number is 717-263-5147.

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Heads Up, Caregivers: November is National Caregivers' Month

Caring for a loved one with PD can be a challenging job, especially as the disease progresses. Former caregivers of a loved one with PD suggest doing the following: **Get prepared, Take care of yourself, Get help** (don't try to do it all yourself), **Work to maintain a good relationship with your loved one**, and **Encourage the person with PD for whom you care, to stay active.**

Preparing for caregiving starts with education. Reading the fact sheet at this link is a good start:

<https://www.caregiver.org/parkinsons-disease-caregiving>

I have a limited number of hard copies of this fact sheet if you do not have access to it on-line.



Nomination for Outstanding Members of the Year – 2016

These awards recognize special individuals in the Hagerstown Parkinson's 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 went to Dave DeHaven and Connie Hipp.

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 January 2017 meeting.



Name of Nominee with Parkinson's Disease: _____

Describe briefly why this individual deserves this award: _____

Name of Nominee who is a Caregiver: _____

Describe briefly why this individual deserves this award: _____

Use another sheet of paper if necessary.

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A New Dyskinesia Drug Will Be Submitted to FDA This Year

Posted by: Holly Teichholtz, September 21, 2016, MJF Foundation Website

A new formulation of amantadine to better treat levodopa-induced dyskinesia (LID) is entering the home stretch. Its developer, Emeryville, California-based biotech Adamas Pharmaceuticals, expects to file an NDA (New Drug Application) with the U.S. Food and Drug Administration later this year.

Dyskinesia can be confusing. These involuntary movements can look like smooth tics or an uncoordinated dance, and may be part of how people think of Parkinson's disease. But they are not part of the disease itself. Dyskinesia is a side effect of levodopa — the gold standard medication for Parkinson's motor symptoms tremor and rigidity — and can significantly impact quality of life.

"If we could control dyskinesia, it would probably be the biggest change in terms of how we treat patients," said Susan Bressman, MD, chair of the Department of Neurology at Beth Israel Medical Center in New York City, in an MJFF video on dyskinesia.

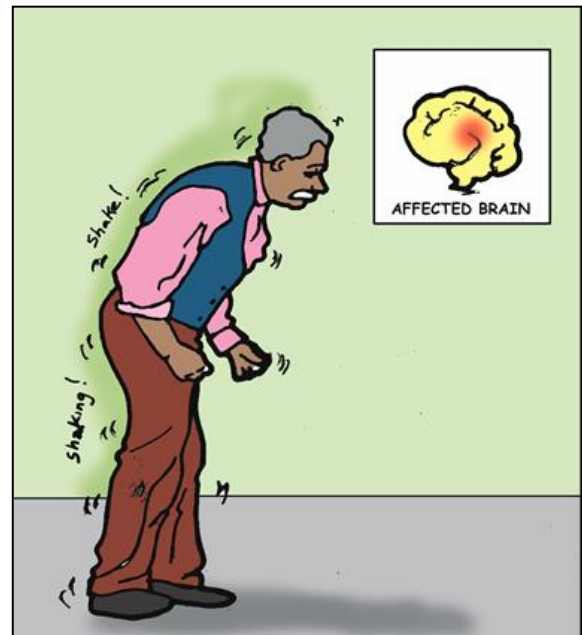
Physicians have long thought that dyskinesia arose with long-term use of levodopa, so patients may delay starting medication and live with disabling symptoms in an attempt to "save" the window of efficacy before dyskinesia begins. While more recent research is showing that levodopa-induced dyskinesia may be influenced more by stage of disease than length of medication use, a treatment for this side effect would be a game-changer for many patients.

According to Nasdaq:

"Data from the study demonstrated a statistically significant reduction in LID at 12 weeks in patients receiving ADS-5102 compared with placebo, as assessed by the Unified Dyskinesia Rating Scale (UDysRS). The candidate was safe and generally well tolerated. The study met its primary endpoint.[...] Results from the study showed an improvement in activities of daily living (ADLs) in PD patients."

Amantadine is approved as a treatment for influenza, but physicians have used it to treat dyskinesia. The drug blocks receptors of neurotransmitter glutamate, which scientists believe is involved in causing this side effect. This extended-release formulation could help control dyskinesia throughout the day.

As FoxFeed reported in December 2015, the company measured the impact of the drug using a new dyskinesia rating scale developed by Chris Goetz, MD, and Glenn Stebbins, PhD, of Rush University Medical Center with support from The Michael J. Fox Foundation..



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Duopa (carbidopa and levodopa) Enteral Suspension

Company: [Abbvie](#)

Approval Status: Approved January 2015

Specific Treatments: motor fluctuations in patients with advanced Parkinson's disease

General Information

Duopa is an enteral suspension of carbidopa and levodopa. Carbidopa inhibits the decarboxylation of peripheral levodopa, making more levodopa available for delivery to the brain. Duopa is specifically indicated for the treatment of motor fluctuations in patients with advanced Parkinson's disease.

Duopa is supplied as a solution for enteral infusion. Duopa is administered over a 16-hour infusion period. The maximum recommended daily dose of Duopa is 2000 mg of levodopa (i.e., one cassette per day) administered over 16 hours. Prior to initiating Duopa, convert patients from all forms of levodopa to oral immediate-release carbidopa-levodopa tablets. Titrate total daily dose based on clinical response for the patient. Administer Duopa into the jejunum through a percutaneous endoscopic gastrostomy with jejunal tube (PEG-J). Please see drug label for specific dosing instructions.

Clinical Results

The FDA approval of Duopa was based on a randomized, double-blind, double-dummy, active controlled, parallel group, 12-week study in 66 patients with advanced Parkinson's disease who were levodopa-responsive and had persistent motor fluctuations while on treatment with oral immediate-release carbidopa-levodopa and other Parkinson's disease medications. Patients were eligible for participation in the studies if they were experiencing 3 hours or more of "Off" time on their current Parkinson's disease drug treatment and they demonstrated a clear responsiveness to treatment with levodopa. Patients were randomized to either Duopa and placebo capsules or placebo suspension and immediate-release carbidopa-levodopa 25/100 mg capsules.

Patients in both treatment arms had a PEG-J device placement. Duopa or placebo-suspension was infused over 16 hours daily. "Off" time was normalized to a 16-hour awake period. The mean score decrease (i.e., improvement) in "Off" time from baseline to Week 12 for Duopa was significantly greater ($p=0.0015$) than for oral immediate release carbidopa-levodopa. Additionally, the mean score increase (i.e., improvement) in "On" time without troublesome dyskinesia from baseline to Week 12 was significantly greater ($p=0.0059$) for Duopa than for oral immediate-release carbidopa-levodopa.

Side Effects

Adverse effects associated with the use of Duopa may include, but are not limited to complication of device insertion, nausea, depression, peripheral edema, hypertension, upper respiratory tract infection, oropharyngeal pain, and incision site erythema.

Mechanism of Action

Duopa is an enteral suspension of carbidopa and levodopa. Carbidopa: When levodopa is administered orally, it is rapidly decarboxylated to dopamine in extracerebral tissues so that only a small portion of a given dose is transported unchanged to the central nervous system. Carbidopa inhibits the decarboxylation of peripheral levodopa, making more levodopa available for delivery to the brain. Levodopa: Levodopa is the metabolic precursor of dopamine, does cross the blood-brain barrier, and presumably is converted to dopamine in the brain. This is thought to be the mechanism whereby levodopa treats the symptoms of Parkinson's disease.

Additional Information

For additional information regarding Duopa or advanced Parkinson's disease, please visit <https://www.duopa.com/>

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Reminders of upcoming events as of Sunday, November 06, 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:

- Wednesday, November 9, 2016, 6:00 PM – 8:30 PM, Johns Hopkins PD Surgical Treatment: DBS and Duopa
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795. Email ggray8@jhmi.edu.
- Wednesday, November 16, 2016, 7:00 – 9:00 PM, Johns Hopkins PD Community Education Series
Subject: Memory & Cognition (Dr. Liana Rosenthal, MD)
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795 Email ggray8@jhmi.edu. Register
- Thursday, November 17, 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 dku-kor@ahcglobal.com.
- Friday, November 18, 2016, 9:00 AM – 12 Noon, Johns Hopkins PD Newly Diagnosed Forum
St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
Contact: Phone 410-955-8795 Email ggray8@jhmi.edu.
- Monday, November 21, 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.

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- Thursday, December 1, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Group Discussion and Party.
- Monday, December 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.
- Thursday, December 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.
- Thursday, January 5, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Breakout Sessions, Patients and Caregivers
- Monday, January 16, 2017, 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.
- Thursday, January 26, 2017, 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.

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

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

-----Cut Out and Save-----

Hagerstown Parkinson's Support Group 2017 Speaker Schedule

Date	Speaker
January 5	Patients & Caregivers Breakout Sessions
February 2	Daniel Quirk, DPT, Regional Director, FOX Rehabilitation
March 2	Jaclyn Garrish, MS, CCC/SLP, Speech-Language Pathologist, Total Rehab
April 6	Sandra Mertz, Lunbeck, Neurogenic Orthostatic Hypotension
May 4	Patients & Caregivers Breakout Sessions
June 1	Colleen Brown, RN, BSN, Clinical Specialist for Medtronic DBS
July 6	TBD
August 3	Becky Dunlop, RN, BSN, Johns Hopkins Movement Disorder Center
September 7	Patients & Caregivers Breakout Sessions
October 5	Dr. Stephen Ryan, Physical Therapist
November 2	Dr. Kelly Mills, Movement Disorder Specialist, Johns Hopkins
December 7	Christmas Party -- No Speaker