

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2017

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

Volume 7, Issue 1

[Visit us on Facebook](#)

This Month's Meeting

January Meeting

Local Support Group Contacts

There were **48** people at our December meeting. A very nice turn out considering so many of our regulars are among the sick and walking wounded. We hope all of those under the weather or in a facility for rehab get well soon and have a great holiday. We are thinking and praying for all of you.

Thanks to Dave and Patsy (and others) for decorating our Christmas tree. It looked very festive. And thanks to all of you who helped get the meeting set up and packed up afterwards. You all were very generous in contributing a "Christmas" gratuity to the staff. Over \$90 was collected for the women who take care of us.

We had a fun time celebrating the Holidays with a *Christmas Family Feud Game* based on the popular TV game show. Everyone enjoyed the game and came up with a lot of "good answers" that amused all of us. **Linda Wilke** won the game by a large margin, scoring 660 points. For scoring the most points, Linda won a \$10 gift certificate donated to the group by the owners of the Western Sizzlin' Restaurant. Dory Kennedy came in second with 600, for honorable mention.

That was followed by the exchange of gifts. Everyone enjoyed opening the surprise presents and discovering what their gift was.

Bill Wilhide won the \$10 gift certificate donated to the group by the owners of the Western Sizzlin' Restaurant. Thanks to Paul and his family for being so generous.

Thanks to **Ecile Shaw** for delivering a silent prayer for all of us before lunch.

MARK YOUR CALENDARS

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

Thursday, January 5, 2016, 11:45 AM

**Patients and Caregivers
Breakout Sessions**

Newsletter Highlights

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

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

Christmas Party Photos ([Page 5](#))

PD Linked to Microbiome ([Page 6](#))

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

Future Meetings

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
Jun 1, Colleen Brown, RN, BSN, Medtronic DBS
Jul 6, TBD
Aug 3, Becky Dunlop, RN, BSN, Hopkins MDC
Sep 7, Patients & Caregivers Breakout Sessions
Oct 5, Dr. Stephen Ryan, Physical Therapist
Nov 2, Dr. Kelly Mills, Movement Disorder Specialist, Johns' Hopkins University
Dec 7, Christmas Party & Gift Exchange

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, December 19th 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. And thanks to the Western Sizzlin' Restaurant for allowing us to set up on their parking lot in November.

A. Candice Valencia

PD Group Bowling

We will not be bowling this month 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 December

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 Bedroom – Setting Up the Bedroom

The bed should be low enough for you to get in easily. A good guideline is for the bed to be 22 inches high, but take your height into account. If the bed is lower than knee level, it probably will be difficult getting in and out. If the bed is too low, you can buy or make risers. If it is too high, you will probably need a carpenter or other skilled person to cut off the legs evenly.

If nighttime incontinence creates occasional problems, buy a plastic mattress cover or a store where baby products are sold. The pad goes on the mattress in the middle of the bed and covered with a fitted sheet. Or make the bed with two fitted sheets, placing a water-proof pad between the sheets. If the top sheet gets soiled, remove it and the pad and you have a clean bed in a flash.

Other tips: If the person with PD spends a lot of time in the bedroom, make it as pleasant as possible with flowers, photographs, etc. Use an insulated travel container with a built in "straw" for water and ice near the patient. Hang shoes by their laces or straps on the handle of your closet to keep them out of the way and easy to get to without bending over.

This and That Thoughts on my Mind by Art Guyer:

Happy holidays to everyone. Doris and I want to thank all of you for the support, prayers, kind words, cards, gifts, and love you have given us this year. It has been a hard 6 months and isn't over yet, but we know you all will be there for us.

Another year has gone by. They pass so quickly now. Last year we started a member recognition program and presented outstanding member awards to Dave DeHaven and Connie Hipp. I'm so glad we recognized Connie last year because she was such a big help to our group – and she passed away this year.

Again this year we will continue our recognition program. More red lanyards will be awarded and mounted certificates will be presented to outstanding members at our January meeting. Please come out to this meeting to show your support and recognition of the winners you selected.

I hope to see all of you there.

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: HOW CAN I HELP MANAGE MY LOVED ONE'S CARE?

Michael J. Fox Foundation

Become an integral part of your loved one's experience with Parkinson's by offering to help share the responsibilities associated with the disease including doctor appointments, therapy sessions, medication administration, household duties or any activity that's more difficult to perform because of Parkinson's disease. People with Parkinson's will desire different levels of assistance and some wish to maintain as much independence as possible. You won't know if a person wants help unless you ask but then respect their response. Communication about these issues is key to understanding how best to help your loved one.

Ask your loved one if you can attend doctor's visits. Care partners play a major role on the team of people treating Parkinson's. You offer an outside view of how your loved one has been doing in the interim since the last visit. You may also recognize new symptoms or subtle changes that the person experiencing Parkinson's doesn't. For example, your loved one's mood or behaviors may have changed and he or she may be more withdrawn. These could be signs of depression, which is a clinical symptom of PD and is treatable with medication. A person with Parkinson's might otherwise dismiss this as a reaction to the diagnosis of PD or not even mention it to the doctor. You may also have noticed that your loved one's speech has become softer or more monotone. This may impact your ability to communicate and therefore your relationship. Speech therapists can prescribe exercises to improve voice control.

You and your loved one can decide together on management options offered and with two sets of ears tuning in, you can both be clear on the treatment plan.

As a caregiver, keeping track of all the details associated with medical care can be overwhelming. Here are some tips to help:

- **Stay organized** with a calendar that you can take on doctor visits. Note doctor and therapy appointments, start and stop dates of medicines, and any side effects you notice.
- **Keep a list** of all doctors' phone numbers and addresses in case of an emergency. Keep a separate and updated list of all prescription medications, their dosages and instructions and prescribing provider. Note allergies or medication intolerances as well.
- **Familiarize yourself** with the terms of your loved one's medical insurance. Know what services, including prescription medication coverage and therapy session benefits, are included. Talk with your physician about the long-term needs of your loved one, and make sure his or her current medical plan will meet those needs. Engage the services of a social worker if you need help navigating these issues.
- **Know your rights** in terms of disability coverage, family leave and elder rights.

If possible, consult a movement disorder specialist, a neurologist specially trained in Parkinson's disease and other movement disorders. Before appointments, prepare a list of your questions for the doctor.

Particularly in the early days after diagnosis, your list may include questions on:

- long-term prognosis
- symptoms you need to be aware of -- both motor and non-motor
- how existing medical conditions may affect the health of your loved one
- medicine protocol
- non-medical treatments
- clinical studies that need you or your loved one with Parkinson's

You do not need special medical training to help with any but the most advanced stages of the disease. Most caregivers are primarily called on to aid with daily tasks that may become difficult or impossible for someone with Parkinson's, and to provide ongoing emotional support. One exception: if Parkinson's causes trouble swallowing and therefore increases the risk of choking, knowing the Heimlich maneuver can be life-saving.



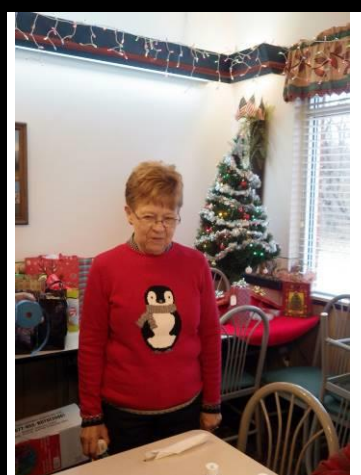
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Christmas Party Photos



December 1, 2016

To see larger versions of these photos, click here: <http://bit.ly/2g62bl6>

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Parkinson's Disease Linked To Microbiome

December 2, 2016

Caltech scientists have discovered a functional link between bacteria in the intestines and Parkinson's disease (PD). The researchers show that changes in the composition of gut bacterial populations—or possibly gut bacteria themselves—are actively contributing to and may even cause the deterioration of motor skills that is the hallmark of this disease.

The work -- which has profound implications for the treatment of PD -- was performed in the laboratory of Sarkis Mazmanian, the Luis B. and Nelly Soux Professor of Microbiology and Heritage Medical Research Institute Investigator.

PD affects 1 million people in the US and up to 10 million worldwide, making it the second most common neurodegenerative disease. Characteristic features of PD include symptoms such as tremors and difficulty walking, aggregation of a protein called alpha-synuclein (aSyn) within cells in the brain and gut, and the presence of inflammatory molecules called cytokines within the brain. In addition, 75 percent of people with PD have gastrointestinal (GI) abnormalities, primarily constipation.

"The gut is a permanent home to a diverse community of beneficial and sometimes harmful bacteria, known as the microbiome, that is important for the development and function of the immune and nervous systems," Mazmanian says. "Remarkably, 70 percent of all neurons in the peripheral nervous system -- that is, not the brain or spinal cord -- are in the intestines, and the gut's nervous system is directly connected to the central nervous system through the vagus nerve. Because GI problems often precede the motor symptoms by many years, and because most PD cases are caused by environmental factors, we hypothesized that bacteria in the gut may contribute to PD."

To test this, the researchers utilized mice that overproduce aSyn and display symptoms of Parkinson's. One group of mice had a complex consortium of gut bacteria; the others, called germ-free mice, were bred in a completely sterile environment at Caltech and thus lacked gut bacteria. The researchers had both groups of mice perform several tasks to measure their motor skills, such as running on treadmills, crossing a beam, and descending from a pole. The germ-free mice performed significantly better than the mice with a complete microbiome. "This was the 'eureka' moment," says Timothy Sampson, a postdoctoral scholar in biology and biological engineering and first author on the paper. "The mice were genetically identical; both groups were making too much aSyn. The only difference was the presence or absence of gut microbiota. Once you remove the microbiome, the mice have normal motor skills even with the overproduction of aSyn."

"All three of the hallmark traits of Parkinson's were gone in the germ-free models," Sampson says. "Now we were quite confident that gut bacteria regulate, and are even required for, the symptoms of PD. So, we wanted to know how this happens." When gut bacteria break down dietary fiber, they produce molecules called short-chain fatty acids (SCFAs), such as acetate and butyrate. Previous research has shown that these molecules also can activate immune responses in the brain. Thus, Mazmanian's group hypothesized that an imbalance in the levels of SCFAs regulates brain inflammation and other symptoms of PD. Indeed, when germ-free mice were fed SCFAs, cells called microglia—which are immune cells residing in the brain—became activated. Such inflammatory processes can cause neurons to malfunction or even die. In fact, germ-free mice fed SCFAs now showed motor disabilities and aSyn aggregation in regions of the brain linked to PD.

In a final set of experiments, Mazmanian and his group collaborated with Ali Keshavarzian, a gastroenterologist at Rush University in Chicago, to obtain fecal samples from patients with PD and from healthy controls. The human microbiome samples were transplanted into germ-free mice, which then remarkably began to exhibit symptoms of PD. These mice also showed higher levels of SCFAs in their feces. Transplanted fecal samples from healthy individuals, in contrast, did not trigger PD symptoms, unlike mice harboring gut bacteria from PD patients. "This really closed the loop for us," Mazmanian says. "The data suggest that changes to the gut microbiome are likely more than just a consequence of PD. It's a provocative finding that needs to be further studied, but the fact that you can transplant the microbiome from humans to mice and transfer symptoms suggests that bacteria are a major contributor to disease."

The findings have important implications for the treatment of Parkinson's, the researchers say. "For many neurological conditions, the conventional treatment approach is to get a drug into the brain. However, if PD is indeed not solely caused by changes in the brain but instead by changes in the microbiome, then you may just have to get drugs into the gut to help patients, which is much easier to do," Mazmanian says. Such drugs could be designed to modulate SCFA levels, deliver beneficial probiotics, or remove harmful organisms. "This new concept may lead to safer therapies with fewer side effects compared to current treatments."

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Reminders of upcoming events as of Sunday, December 04, 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 Silvius, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 rd Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
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:

- Thursday, December 15, 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.
- 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, 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 dku-kor@ahcglobal.com.
- Thursday, February 2, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Daniel Quirk, Regional Director of FOX Rehabilitation.

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- Monday, February 20, 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, February 23, 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.
- Thursday, March 2, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Jaclyn Garrish, MS, CCC/SLP, Speech-Language Pathologist, Total Rehab.
- Monday, March 20, 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, March 23, 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 at 301-639-3166 or dkukor@ahcglobal.com.
- Thursday, April 6, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Sandra Mertz, Lunbeck, Neurogenic Orthostatic Hypotension.

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