Hagerstown, MD and the Four-State Area

### February 2017

### This Month's Meeting

There were **46** people at our January meeting, including 5 new people. This meeting was designed to have breakout discussions for Caregivers and Patients. A speaker from Brook Lane, Melissa Jackson, provided information to the Caregivers.

**Joyce Garland** 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 the prayer for all of us before lunch.



At this meeting, annual awards were given also. See <u>page 5</u> for photos of the memmembers.

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For those of you who have been with us for a while, you certainly know **Becky Dunlop**, Associate Director of the Johns Hopkins Movement Disorder Center. She has announced she is retiring from JHU after 19 years there and will begin working for the Baltimore County Health Department on a part-time basis. She has devoted so much to the PD community and has worked long, hard hours; now she wants to balance her work life a little better with some personal needs. We all wish you well Becky.

Dean Cook, Meeting Facilitator Hagerstown Parkinson's Support Group 497 Hogan Drive Martinsburg, WV 25405 Phone: 304-268-1623 Email: <u>home2wv@yahoo.com</u> Visit Our Website at: www.fareshare.net/Parkinsons/

Monthly Newsletter

Visit us on Facebook

### **February Meeting**

### MARK YOUR CALENDARS

Join us for our next Parkinson Support Group Meeting at the

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, February 2, 2017, 11:45 AM

Daniel Quirk, DPT, Fox Rehabilitation

#### Newsletter Highlights Tips for Making Life Easier (Page 3) Heads Up, Caregivers! (Page 4) Members Awards Photos (Page 5) The 21st Century Cures Act and PD (Page 6) Detailed Event Listing (Pages 7 & 8)

### **Future Meetings**

#### 2017

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, Dory Kennedy, Right at Home Aug 3, TBD 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

### Volume 7, Issue 2

### Local Support Group Contacts

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

<u>Cumberland Parkinson's Support Group</u> 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

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

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

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

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

### Attend a Support Group Meeting

See Page 3 for a New Support Group in Chambersburg Starting in February

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.

Hagerstown, MD and the Four-State Area

## **Monthly Newsletter**

### **Caregiver's Breakfast**

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month.

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

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

### **Need Transportation?**



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 <u>the entire day</u>, then we will not have our regular monthly meeting. Also, I will send an email out by midmorning 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.

### Sandy Phillips

On Don's death Sandy sent the following note to the Hagerstown Parkinson's Support Group:

"I wish to thank each and every one for the support shown for Don and myself when he was ill. And to everyone who expressed their sympathy at the time of Don's death. Your group has been a blessing."

Thank you. Sandy Phillips and Family

## February 2017

### **PD Group Bowling**

We will be bowling this month – on January 20<sup>th</sup> at 1:00 PM.

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 <u>vour</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.

Barb needs some good thoughts too. She broke a bone in her ankle recently and



her ankle recently and cannot drive or get around very well.

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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

**Consider repositioning your bed against the wall** to make it more accessible. Install a grab bar on the wall alongside the bed, about 10 inches higher than the mattress. Be sure to anchor the bar to studs in the wall so it will be secure. Or look into obtaining half bed rails that can be installed under the mattress. Installing such rails might eliminate the need for an expensive hospital bed with bed railings.

Attach a bed pull to the grab bar or to the frame at the foot of your bed to assist in turning over and getting out of bed. The pull should be long enough for you to reach but still at arm's length for good leverage when you want to pull yourself out of bed. Tie a large wooden ring to the end to serve as a handhold. Sew a binder clip near the ring to clamp it to the bedding. Bed pulls can also be attached to the side of the bed for assistance in turning.

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

Dave DeHaven and I are very busy these days. Doris' broken leg did not heal properly and she had a partial hip replacement early this month at Johns Hopkins. She is to be released to a rehab facility. Patsy DeHaven continues to have stomach pain and other issues with her feeding tube. Please keep us in your thoughts and prayers as we go into the new year facing these challenges. And thank you for the emails, phone calls and cards wishing us well.

As a result, I was not able to attend the January meeting, but Dave was there and facilitated the meeting. Dean Cook facilitated the patients breakout session. Dean has also graciously agreed to facilitate the group meetings beginning in February. Dean and I have agreed that we will work through this opportunity together, he will run the meetings and I will handle the administrative/computer work which I can do from home. It was a great relief to Dave and I when Dean agreed to do this; we are putting the meetings in the hands of someone who is not only capable of doing it, but has already got a head start on this kind of activity with his work as the MAPS Ambassador. When accepting this "job" Dean said: "Thanks for your confidence in me, Art, and rest assured that I will try to maintain the high standards you have set for the group. Under no circumstances can we fail to provide the encouragement, information, and downright good time these folks have come to expect. We can get thru this."

So now I need to ask those of you who attend the meetings to also step up and help get us through this period. Many of you already assist us at the restaurant, and I know you will continue to help. I wish I knew how long we are talking, but it is impossible to tell at this point. Whoever runs the meetings needs your help. Dean's contact information is on the first page of this newsletter. Please wish him well when you see him!

Take care ..... Art

### **PD Exercise Class and Support Group**

A new Parkinson's Support Group will begin meeting in Chambersburg, PA on February10, 2017 at 4:00 pm. The location is at Physical Therapy Etc., right behind the new Sheetz building on 142 Franklin Farm Lane. At the first meeting the presentation will be on the LSVT BIG program and the positive impact of exercises on Parkinson's management. The contact person is Jan Benedick, PT, at (717) 263-5147 and by email at jbenedick@physicaltherapyetc.com.



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### Heads Up, Caregivers: Parkinson's Disease: Guide to Caregiving

Written by Kimberly Holland

People with Parkinson's disease rely on caregivers for a wide range of support — from driving them to doctor's appointments to helping them get dressed. But the person with Parkinson's disease isn't the only one who should be cared for. Caregivers must take care of themselves too. Being a caregiver can be a complicated and physically and emotionally draining experience.

Here are five ways to handle your role as a caregiver, without neglecting your own well-being.

**1. Be Involved**. Doctors strongly encourage caregivers to attend doctor's appointments. Your input may help the doctor understand how the disease is progressing, how the treatments are working, and what side effects are occurring. As Parkinson's disease progresses, dementia may make the patient's memory worse. By going to the appointment, you can help remind your loved one what the doctor said or instructed. Your role during this time is especially important to the treatment plan.

**2. Establish a Team**. Many family members, friends, and neighbors will help if you need to run errands or just take a break. Keep a handy list of people you can call on occasionally when you need help. Next, designate whom you should call for certain situations. Some people may be more helpful with certain tasks, like grocery shopping, mailing packages, or picking up children from school.

**3.** Look for a Support Group. Caring for a loved one can be deeply satisfying. It's a chance for your family to draw together as you face the challenges of Parkinson's disease head-on. However, providing emotional and physical care for someone with an illness can become stressful and, at times, overwhelming. Balancing your personal life with caregiving can be difficult. Many caregivers will face periods of feeling guilty, angry, and abandoned. The person you're caring for will likely also benefit from being part of a support group. These groups allow for open communication with other people facing the same struggles. They also provide an opportunity to share suggestions, ideas, and tips among the group members.

**4. Seek Professional Assistance**. In the latter stages of Parkinson's disease, caring for your loved one may become more difficult. When this happens, you may need to seek professional care. Certain symptoms and side effects of Parkinson's disease may be best treated with professional assistance or home health nurses, or in a nursing home environment. These symptoms and side effects include difficulty walking or balancing, dementia, hallucinations, and severe depression. Several organizations, including The National Alliance for Caregiving and the National Family Caregiver Association, provide assistance and care specifically to caregivers. These caregiver support groups offer education seminars, enrichment resources, and connections to other individuals in similar situations.

**5. Care for the Caregiver**. Parkinson's disease begins very slowly, and the role of caregiving is often thrust on a person with very little warning or preparation. It's important for the caregiver to become familiar with all aspects of the disease to ensure better care for the patient and an easier transition for the caregiver. When a loved one is diagnosed with PD, treatment for the disease should begin almost immediately. This is a time of major change not only for the person with PD but also for the caregiver. Whether you're a spouse, parent, child, or friend, your role as a caregiver is to be on call 24/7. You'll likely feel as if your entire world revolves around your loved one, while your personal life takes a backseat. Eating a balanced diet, exercising regularly, and getting proper sleep are just three things you can do to stay in shape.

**Caregiver Support Group:** The Commission on Aging has a Caregiver Support Group that meets quarterly at the Commission on Aging. It is free to attend. This newly formed group is meant to serve as a means of support for those who give of themselves as caregivers. It will give caregivers an opportunity to learn about community resources available and will give them the opportunity to connect with others who understand the caregiving journey.

Save the Date for the next meeting scheduled for April 11 @ 10:00 a.m. (Call 301-790-0275 ext. 221) Topic: Dynamics of Family Caregiving and the roles that Family Member takes on. Speaker: Chis Fisher, Delegating RN at Right at Home In-Home Care and Assistance.

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### **Members' Awards Photos**



Dave DeHaven presenting a Special Service Award for 2016 to Carol and Dean Cook, January 5, 2017





Dave DeHaven presenting Outstanding Member of the Year 2016 to Dean Cook, January 5, 2017



Dave DeHaven presenting Outstanding Member of the Year 2016 to Ecile Shaw, January 5, 2017

In addition we want to recognize Aura and Chuck Bihun, Jay Stouffer, and Patsy and Dave DeHaven for perfect attendance in 2016. Also, Red Lanyards were awarded to Aura and Chuck Bihun, Chet Fabijanski, and Bill and Marquita Storms for their continued support to our group.

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### **Monthly Newsletter**

## February 2017

### The 21st Century Cures Act and Parkinson's Disease

MJFF, Posted by <u>Allyse Falce</u>, December 13, 2016



On December 13, 2016, President Obama signed the 21st Century Cures Act into law. A number of key provisions in the bill, which will directly impact the Parkinson's community, are highlighted here.

Develop infrastructure to collect data on neurological diseases to better understand who is living with these conditions, facilitate research and plan for health care needs.

The 'Cures' bill creates the National Neurological Conditions Surveillance System at the Centers for Disease Control and Prevention (CDC) to collect demographic information on people living with neurological diseases. We do not currently have accurate information about how many people are living

with Parkinson's disease, where they are located or who they are (their gender, ethnicity, etc.). Lack of this core data slows research and makes it difficult to ensure health care services are properly allocated. The database will provide a foundation for understanding many factors, such as clusters of diagnoses in certain geographic regions, variances in the number of men and women diagnosed with neurological diseases, and differences in health care practices among patients.

## Support research initiatives to further our knowledge of the brain and develop individualized treatments, which can lead to better treatments and health outcomes.

"Cures" allocates \$1.5 billion over ten years to the National Institutes of Health (NIH) for the BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative, which supports the development and application of unique technologies to help researchers better understand the brain and treat conditions such as Parkinson's, Alzheimer's and depression. The bill also provides the NIH with \$1.5 billion over ten years for the Precision Medicine Initiative (PMI). Most medical treatments are designed for the average patient, but this one-size-fits-all approach might not be ideal. This Initiative aims to develop ways to tailor prevention strategies and treatments to an individual's unique genes, environment and lifestyle. Advances in precision medicine could be particularly beneficial for people with Parkinson's, each of whom has a unique set of symptoms and experience with the disease.

## Expedite Food and Drug Administration (FDA) approval of regenerative medicines (cell therapies), without lessening the FDA's existing strict regulatory standards or authority.

The bill provides the FDA with flexibility to consider the unique attributes of regenerative medicine products (as compared to standard drug and device therapies) throughout the review process. This could potentially accelerate approval but would not compromise the agency's high standards for ensuring a therapy's safety and efficacy. "Cures" allocates \$30 million for clinical research to further the field of regenerative medicine using adult stem cells. Stem cell research in the field of Parkinson's could lead not only to symptomatic therapies but also a deeper understanding of the disease.

#### Institutes reforms at and provides additional funding for the Food and Drug Administration to improve access to care.

"Cures" requires the FDA to take patient perspectives into account in the drug approval process and tasks the agency with creating a framework for collecting patient experience data. This data includes information collected by various sources (patients, family members and caregivers, patient advocacy organizations, disease research foundations, researchers and drug manufacturers) that details a pa-

tient's experience with a disease or therapy and the impact it has on their lives. Patient preferences regarding the treatment of their disease will also be assessed. Involving patients in this manner will put government regulators in touch with the community's experiences and priorities as new drugs and devices enter late-stage clinical testing and move toward FDA approval. The bill also creates an accelerated review process for breakthrough medical devices that offer significant advantages over the currently available products and those that could benefit patients with life-threatening or debilitating conditions. Combination therapies (those that are both a drug and device) will be eligible for a streamlined review process. Both reforms will speed patient access to certain device therapies.



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### Reminders of upcoming events as of Thursday, January 12, 2017

### **REGULAR EVENTS:**

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 <sup>st</sup> Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 <sup>st</sup> 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 <sup>nd</sup> 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 <sup>nd</sup> 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 <sup>rd</sup> Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Frederick PD Support Group Monthly Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM 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 <sup>rd</sup> Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 bergstromdf@gmail.com
Cross Keys Parkinson's Support Group	3 <sup>rd</sup> Thursday @ 2:15 PM Cross Keys Village, New Oxford, PA	Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net

### **OTHER EVENTS:**

- <u>Monday, January 16, 2017, 8:30 10:00 AM, Caregivers' Breakfast</u>: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- Friday, January 20, 2017, 1:00 PM 4:00 PM Parkinson Bowling: Duckpins at Southside Bowl at 17325 Virginia Avenue in Hagerstown, MD. For information, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com.
- <u>Thursday, January 26, 2017, Noon 1:00 PM Memory Café</u>: Free lunch and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.
- <u>Thursday, February 2, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting</u>: <u>Daniel Quirk, Regional Director of</u> <u>FOX Rehabilitation</u>.
- <u>Monday, February 20, 2017, 8:30 10:00 AM, Caregivers' Breakfast</u>: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Thursday, February 23, 2017, Noon 1:00 PM Memory Café</u>: Free lunch and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

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- <u>Thursday, March 2, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting</u>: Jaclyn Garrish, MS, CCC/SLP, Speech-Language Pathologist, Total Rehab.
- <u>Monday, March 20, 2017, 8:30 10:00 AM, Caregivers' Breakfast</u>: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- <u>Thursday, March 23, 2017, Noon 1:00 PM Memory Café</u>: Free lunch and meeting at the Otterbein Church on East Franklin Street in Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.
- <u>Thursday, April 6, 2017, 11:45 AM, Hagerstown Parkinson's Support Group Meeting</u>: Sandra Mertz, Lunbeck, Neurogenic Orthostatic Hypotension.
- <u>Tuesday, April 11, 2017, 10:00 AM, WCCA Caregiver Support Group meeting</u>. Topic: Dynamics of Family Caregiving and the roles that Family Member takes on. Speaker: Chis Fisher, Delegating RN at Right at Home In-Home Care and Assistance. Call 301-790-0275 ext. 221 for information.

#### 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

-----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	Dory Kennedy, Right at Home, Post Discharge Safety in the Home	
August 3	TBD	
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	