

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

August 2014

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

Volume 4, Issue 8

[Visit us on Facebook](#)

This Month's Meeting

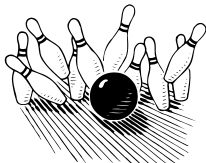
We had 47 attendees at the July 3rd meeting, including 4 new members.

Bailey Vernon, a Health Educator and Senior Research Program Coordinator at the Johns Hopkins Parkinson's Disease and Movement Disorders Center was our featured speaker at this meeting. Bailey has a Master's Degree in Public Health and is a Certified Health Education Specialist. She has been extremely helpful to this support group as well as many others. The topic of her presentation was Cognition and PD.

Bailey's discussion covered the many aspects of cognition in a person with PD, including deficits in attention, mental processing problem solving, memory, language and visual-spatial difficulties. She also covered a number of treatment possibilities for these deficits.

I want to thank **Dick Naugle** for his humorous story and for asking the blessing with a special prayer for Parkinsons.

Harold Burgesser won the \$10 gift certificate to the Western Sizzlin Restaurant donated by **Paul Romsburg** and his family.



Check out the bowling update on page 2.

August Meeting

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the

Western Sizzlin Steakhouse

17567 York Road, Hagerstown, MD
(301) 791-7560

Thursday, August 7, 2014, 11:45 AM

Our August Speaker is
Becky Dunlop
Parkinson's Disease & Movement
Disorders Center, Johns Hopkins

Highlights
[Exercise and PD Management \(Page 3\)](#)
[Levodopa Information \(Page 4\)](#)
[Fall Picnic \(Page 5\)](#)
[Photos from our June 20 Picnic \(Page 6\)](#)
[Detailed Event Listing \(Pages 7 & 8\)](#)

Attend a Support Group Meeting



Upcoming Events

Future Meetings

August 7, Becky Dunlop, JHM Nurse Coord.
September 4, Dr. Paul Dash, JH Neurologist
October 2, Doug DeHaven, Fire Marshall
November 6, Stephen Ryan, Physical Therapist
December 4, Breakout Sessions

Caregivers' Breakfast

Third Monday of every month, 8:30 AM at the Railroad Junction Family Restaurant. July's breakfast is on the 21st.
Call Art Guyer for information.

A detailed listing of upcoming events is included on [pages 7 and 8](#).

Other Local Support Group Contacts

Berkeley County Parkinson's Support Group
Debi Corbin, Facilitator, 304-886-8594
danicasgma@aol.com

Winchester Area Parkinson's Support Group
Cheryl Reames, 540-662-4632 or
cwreames@gmail.com
<http://www.walkrunmove.org/>
[Winchester Facebook Page](#)

Cumberland Parkinson's Support Group
Shirley McKinney, Facilitator, 301-729-1427
sjmckinney@atlanticbb.net

Chambersburg Parkinson's Support Group
Kathy Smith, 717-377-8320
kathy.smith@embarqmail.com

Frederick PD Support Group
John Kraft and Janet Silvious, Facilitators
301-845-6514
janet@fifpdsg.org
www.fifpdsg.org

The Hagerstown Parkinson's Support Group

Group Facilitator:
Art Guyer
22215 Troy Lane
Hagerstown, MD 21742
240-625-2722
aguyer42@myactv.net

The Hagerstown Parkinson's Support Group
is supported in part by:



17567 York Road Hagerstown, MD
Stop by for lunch or dinner to support them!

Thanks to Paul Romsburg, his family, and staff of the *Western Sizzlin* for supporting our group.

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please contact the Group Facilitator, Art Guyer.

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Caregiver's Breakfast.

Our Caregivers' Breakfasts are on the 3rd Monday of every month. In June, **Mike Saterbak, Ecile Shaw, Barbara Harrell, Sandy Phillips, Dave DeHaven, and Art Guyer** enjoyed the Caregivers' Breakfast.

This month, caregivers will meet for breakfast on July 21, at the Railroad Junction Family Restaurant, at 8:30 AM. The restaurant is located at 301 S. Burhans Blvd E, in Hagerstown.

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.



Birthdays in June

Happy Birthday to 13 of our members who have July birthdays: **Bob DeGrange, Linda Hult, Nancy Starliper, Pat Kaiser, Judy Frantz, Fred Craver, Ragan Shaw, Charles Masters, Mike Saterbak, Barbara Harrell, Jon Pearson, Susan Hoelschen, and Kathy Lange.**

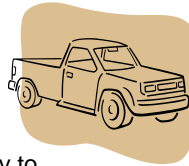
So we can celebrate your birthday at our meetings, contact Art who keeps a master schedule for the group. No years, just month and day!



Need Transportation or Just a Break?

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

If you would like a couple of hours of free time and we can take your spouse for a short day trip, we will be happy to try to work something out for you. Give Art a call or send him an email.



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 has volunteered as the Sunshine Committee of One** and will be responsible for sending out cards as appropriate. Call her at 301-797-7845 or contact Art if you know someone in need.

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Totem Pole Trip

We had a great trip to the Totem Pole Theater in Fayetteville, PA on July 2nd. There were 18 members who made the trip, a dozen of which had dinner together after the show in Chambersburg. The group was recognized during the curtain speech before the show. The Craver's could not make the trip due to health issues, so we hope Norma has recovered by now.



Fall Picnic

On September 12 we will be holding our fall picnic. If you would like to attend, please contact Art by September 8 so we can order the right amount of chicken.



[See Page 5 for details and directions](#)

[And Pages 5 and 6 for photos from our June 20th Picnic](#)

PD Group Bowling

On Thursday, June 26th we had our first "PD Bowling Event." It was at Southside Bowls on Virginia Avenue in Hagerstown. The alleys were set up for those who have difficulty moving, lifting or even walking.

There were 15 members who showed up to participate in the duckpin fun. We divided up into 3 groups and had a great time. Some of us had not bowled for 40 years and then there were some "ringers."



Some of the Participating Members

We plan on doing this again on July 24th at 1:15 PM so join us for the fun and the exercise! Call **Dave DeHaven** at 301-582-2815 for more information and directions.

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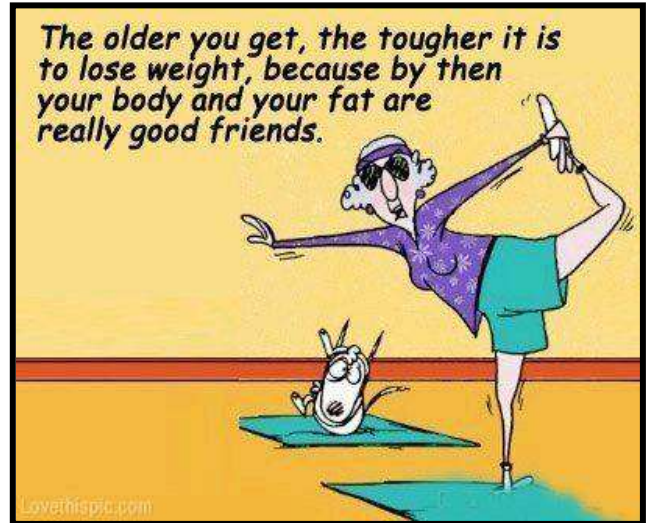
What role does exercise play in the management of PD?

National Parkinson Foundation

Exercise is an important part of healthy living for everyone. However, for people with PD exercise is not only healthy, but a vital component to maintaining balance, mobility and daily living activities. Doing exercise is associated with a better sense of wellbeing, even across stages and severity of the disease. There is a growing consensus amongst researchers about the short- and long-term benefits of exercise for people with PD.

Exercise can benefit in two ways:

- **Symptom management.** Research has shown that exercise can improve gait, balance, tremor, flexibility, grip strength and motor coordination. Exercise such as treadmill training and biking have all been shown to benefit, as has tai chi and yoga (although more studies are needed).
- **Possibly slowing disease progression.** There is a strong consensus among physicians and physical therapists that improved mobility decreases the risk of falls and some other complications of Parkinson's. They agree that practicing movement—physical therapy, occupational therapy, and participating in an exercise program—improves mobility. By avoiding complications, you can avoid some of the things that can make PD worse. Beyond this, we know that people who exercise intensely, for example by doing things like running or riding a bicycle, have fewer changes in their brains caused by aging. Studies in animals suggest that Parkinson's disease is also improved by exercise. Many neurologists in the NPF Center of Excellence network recommend intense exercise to their patients and also to people who are worried about getting PD because of a family connection.



How can I benefit from exercise?

The best way to achieve these benefits is to exercise on a consistent basis. People with Parkinson's enrolled in exercise programs with durations longer than six months, regardless of exercise intensity, have shown significant gains in functional balance and mobility as compared to programs of only two-week or ten-week durations.

However, when it comes to exercise and PD, greater intensity equals greater benefits. Experts recommend that people with Parkinson's, particularly young onset or those in the early stages, exercise with intensity for as long as possible as often as possible. Your doctor might recommend an hour a day three or four times a week, but most researchers think that the more you do, the more you benefit.



Intense exercise is exercise that raises your heart rate and makes you breathe heavily. Studies have focused on running and bicycle riding, but experts feel that other intense exercise should provide the same benefit.

Regardless of your condition, you should always warm up and cool down properly, exercise in a way that is safe for you, and know your limits. There are many support groups, therapists, and exercise programs who can help with PD-safe exercise and help you to set up your own program if that works best for you. Be sure to consult your physician. If your physician is not a PD expert, you can call the NPF helpline (1-800-4PD-INFO) to help you to explain to your physician the importance of exercise so you and your doctor can put together a plan that will work for you.

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Levodopa Shows Slight Edge as Initial Treatment for Parkinson's

PFNCA, June 10, 2014

People who took levodopa (which is usually prescribed as Sinemet®) as their initial therapy after a Parkinson's disease (PD) diagnosis reported, over the long term, slightly better mobility and quality of life than those who began treatment with other classes of PD drugs. The results from the largest clinical trial comparing these treatments indicate those who started PD treatment with levodopa reported slightly better results than those who began treatment with either dopamine agonists, such as ropinirole (Requip®) or pramipexole (Mirapex®), or monoamine oxidase type B (MAO-B) inhibitors, including selegiline (Eldepryl®) or rasagiline (Azilect®).

There has been disagreement about which treatment for Parkinson's is most beneficial as an initial therapy. Some people with Parkinson's and their doctor opt for levodopa, the long time gold standard therapy which provides the best relief for movement symptoms as the disease progresses. But after taking this drug for five or more years, about a quarter of people develop involuntary movements, called dyskinesia. Some doctors, in an attempt to avoid negative long-term impact and potentially delay dyskinesia have opted to first take alternatives to levodopa. But dopamine agonists can lead to side effects including nausea, hallucinations, swelling of the legs, sleep difficulties, and impulse control disorders. And MAO-B inhibitors have only a modest impact on motor symptoms.

The UK PD MED Collaborative Group, set out to discover which of the three classes of drug leads to the best outcomes for people with PD, both in the short term and over the course of several years. The study recruited 1,620 people with early stage PD to participate in a clinical trial. They randomly assigned roughly one-third of the study participants to receive only one of the three therapy types – levodopa, dopamine agonists or MAO-B inhibitors – as their first PD medication. The study was open-label; meaning that the medical personnel and the people being treated all knew which therapy was being given. At baseline, and at regular intervals up to seven years after starting treatment, study participants filled out standard evaluations of mobility, quality of life, and cognition.

Results:

- People taking levodopa consistently reported a very small, but statistically significant better quality of life and milder motor symptoms than people taking other treatments, both soon after beginning therapy and in the long term, up to seven years.
- People initiating treatment with MAO-B inhibitors reported slightly more improvement in mobility than those who started with dopamine agonists.
- Side effects led some participants to drop out of the study, including 28 percent of participants taking dopamine agonists, 23 percent of those taking MAO-B inhibitors, and two percent of those taking levodopa.
- The researchers did not observe any decline in levodopa's benefit. There was no evidence for cumulative adverse effects the group treated with levodopa when compared with those treated with dopamine agonists or MAO-B inhibitors.
- Over time, nearly all those who were only taking MAO-B inhibitors or dopamine agonists were also taking levodopa as part of their PD medications.

What Does It Mean?

This study aimed to answer an unresolved question in the treatment of PD, which is: what class of drug is most effective for people with Parkinson's just beginning treatment? The researchers compared three widely-used classes of treatments – levodopa, dopamine agonists and MAO-B inhibitors – to see which one is the best option.

The study found that levodopa works slightly better than MAO-B inhibitors or dopamine agonists as an initial therapy for people with PD. Participants treated with levodopa reported milder motor symptoms and slightly better quality of life than people taking other treatments. However, the differences were so mild that regardless of which therapy a person took first, the effects were very similar long-term. No medically significant short- or long-term benefit was found for initiating therapy with levodopa or one of the alternatives to dopamine. When the overall benefits and risks are considered, the study authors nevertheless suggest that levodopa may be the best initial and long-term therapy for people with PD.

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Levodopa (Continued from Page 4)

What are the take-home messages from this study? First, the fear that people have surrounding levodopa continues to be unfounded. People who took levodopa as an initial therapy in this study developed dyskinesia at nearly the same rate as those who started with the other PD medications. Second, for the seven-year duration of this study, levodopa did not appear to lose its effectiveness nor did it appear to speed disease progression. Third, because MAO-B inhibitors and dopamine agonists are typically more expensive than levodopa, people can confidently make choices based upon cost as well as effectiveness. It is also important to note that all study participants were eventually treated with levodopa regardless of initial therapy assignment.

The major strengths of the current study are its large number of participants and the long duration of follow up. Its major limitations are that people with PD and practitioners were not blinded to the treatment arm. Additionally, since the majority of people in this study were 60 years or older, one unanswered question is which therapy is best for treating people who live with young-onset PD.

All in all, the end result of this study should lay to rest the concerns about levodopa. These results should allow people with Parkinson's and their physicians to choose therapies that make sense clinically as well as financially.

Fall Picnic

When: Friday, September 12, 2014, 12 Noon

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

Bring a covered dish or dessert and there will be fried chicken. Plates, napkins, utensils and drinks are provided.

There will be free bingo for all! Everyone should bring one or more wrapped, inexpensive "prize" for bingo winners. Prizes can be something you want to get rid of or you can pick up some items from a "dollar store."

Directions:

For those using I-81, go East on I-70 at the I-81/70 Interchange

Eastbound on Interstate 70 (from I-81), take Exit 28, turn left on Downsville Pike; turn left at first traffic light. The park entrance is 100 yards past the light, on the left. Follow the park road to the end and the pavilion will be on the right.

Westbound on Interstate 70 (from Frederick), take Exit 28, the park entrance is 100 yards past the first stop light, on the left. Follow the park road to the end and the pavilion will be on the right.

For more information or to make reservations for the picnic,
contact Art by phone at 240-625-2722 or email at aguver42@myactv.net.

Photos of our June 20th Picnic. See [Page 6](#) for more.



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Hagerstown Parkinson's Support Group
Picnic on June 20, 2014

Back (4th) (L to R): Jim Mattern, Jerry Harrell, Kelly Smith, Dick Naugle, Linda Embly, Paul Embly, Ragan Shaw, Dave DeHaven

3rd (L to R): Lu Mattern, Mike Saterbak, Jack Nazelrod, Kathy Smith, Peggy Naugle, Phyllis Davis, Harry Davis, Judy Frantz, Art Guyer, Betty Gladhill

2nd (L to R): Marci Saterbak Dee Nazelrod, Glenda Austin, Ecile Shaw, Barbara Harrell, Evelyn Fuller, Curtis Fuller, Betty Stouffer, Jay Stouffer, Cheryl Reames, Connie Hipp, John Hipp

1st, Seated, (L to R): Jack Nazelrod's Grandson (Camiren), Patsy DeHaven, Doris Guyer

On June 20th we had a great picnic for the group. Beautiful weather, good food, lots of games, and interesting conversation. There were 33 adults in attendance and 6 grandchildren (not all pictured above). The variety of food was amazing – too much to try it all! The bingo was quite popular and there were a lot of donated gifts as prizes. We especially enjoyed having Cheryl Reames, the facilitator from the Winchester PD Support Group, and Kathy Smith, the facilitator from the Chambersburg PD Support Group, spend the afternoon with us. See [Page 5](#) for information on our Fall Picnic.



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Reminders of upcoming events as of Thursday, July 03, 2014

- Tuesday, July 8, 2014 (2nd Tuesday): Winchester PD Support Group Monthly Meeting at the Family Life Center, Winchester Church of God, 2080 N. Frederick Pike, Route 522 North, Winchester, VA at 11:00 AM. **Program:** Sing for Better Health led by Richard Lewellen, Music Therapist. Contact Cheryl Reames for more information at 540-662-4632 or by email at cwreames@gmail.com.
 - Thursday, July 10, 2014: PFNCA Community Meeting at the C. Burr Artz Public Library, 110 East Patrick St., Frederick, MD from 6:30 PM to 7:30 PM. The guest speaker is Dr. Fernando Pagan from Georgetown University Hospital. The purpose of the meeting is to learn more about PD and to discuss the need for programs and services for those impacted by the disease in Western Maryland. RSVP at pfnca@parkinsonfoundation.org.
 - Friday, July 11, 2014 : Cumberland PD Support Group Monthly Meeting and Picnic at the Grace Memorial Community Church in Cumberland, MD at 4:00 PM. Contact Shirley McKinney for more information and directions at 301-729-1427 or simckinney@atlanticbb.net.
 - Tuesday, July 15, 2014: Chambersburg PD Support Group Monthly Meeting at Menno Haven in Chambersburg, PA at 2:00 PM. Becky Dunlop from Johns Hopkins is the featured speaker. Contact Kathy Smith at 717-377-8320 or kathy.smith@embarqmail.com for information or directions.
 - Monday, July 21, 2014 (3rd Monday): Caregivers' Breakfast at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
 - Thursday, July 24, 2014: HPSG Bowling at Southside Bowl, 17325 Virginia Ave, Hagerstown, MD, at 1:15 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
 - Friday, July 25, 2014: HPSG Cards at Dave and Patsy DeHaven's at 1:00 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
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- Thursday, August 7, 2014 (1st Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Becky Dunlop from Johns Hopkins is the featured speaker. Call Art at 240-625-2722 for information or directions.
 - Tuesday, August 12, 2014 (2nd Tuesday): Winchester PD Support Group Monthly Meeting at the Family Life Center, Winchester Church of God, 2080 N. Frederick Pike, Route 522 North, Winchester, VA at 11:00 AM. Speaker: Becky Dunlop, Health Educator from Johns Hopkins University Department of Neurology/Parkinson's Disease & Movement Disorders Center. Contact Cheryl Reames for more information at 540-662-4632 or cwreames@gmail.com.
 - Monday, August 18, 2014 (3rd Monday): Caregivers' Breakfast at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
 - Tuesday, August 19, 2014 (3rd Tuesday): Chambersburg PD Support Group Monthly Meeting at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or kathy.smith@embarqmail.com for information or directions.
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- Wednesday, September 3, 2014: Johns Hopkins Conference Call for Support Group Leaders at 10:00 AM. Details to come.
 - Thursday, September 4, 2014 (1st Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Dr. Paul Dash, Johns Hopkins neurologist, is the featured speaker. Call Art at 240-625-2722 for information or directions.
 - Monday, September 8, 2014: Johns Hopkins Deep Brain Stimulation Educational Session from 6 to 8 PM. Information and discussion on the potential benefits of DBS. Call Bailey Vernon at 410-616-2811 for information and to register.

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- Friday, September 12, 2014: HPSG Fall Picnic at Snook Memorial Park in Hagerstown, MD at 12 Noon. Call Art at 240-625-2722 for information or to register.
 - Monday, September 15, 2014 (3rd Monday): Caregivers' Breakfast at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
 - Tuesday, September 16, 2014 (3rd Tuesday): Chambersburg PD Support Group monthly meeting at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or kathy.smith@embarqmail.com for information or directions.
 - Wednesday, September 17, 2014 (3rd Wednesday): "Friends in Frederick" PD Support Group monthly meeting at 1:00 PM. Held at Mount Pleasant Ruritan Club in Walkersville, MD. Contact Janet Silvious at 301-845-6514 or jsilvious@yahoo.com.
 - Tuesday, September 23, 2014 (4th Tuesday): Berkeley County Parkinson's Support Group monthly meeting at 6:30 PM at the *Otterbein United Methodist Church of Martinsburg WV*. Contact Debi Corbin at 304-886-8594 for more information.
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- Thursday, October 2, 2014 (1st Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Doug DeHaven, Hagerstown Fire Marshall, is the featured speaker. Call Art at 240-625-2722 for information or directions.
 - Sunday, October 12, 2014: Partners in Parkinson's Seminar in Washington, DC. Time is 7:45 AM to 3:45 PM. Information and registration is available on this website: <https://www.partnersinparkinsons.org>.
 - Monday, October 20, 2014 (3rd Monday): Caregivers' Breakfast at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
 - Tuesday, October 21, 2014 (3rd Tuesday): Chambersburg PD Support Group Monthly Meeting at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or kathy.smith@embarqmail.com for information or directions.
 - Wednesday, October 22, 2014 (3rd Wednesday): "Friends in Frederick" PD Support Group monthly meeting at 1:00 PM. Held at Mount Pleasant Ruritan Club in Walkersville, MD. Contact Janet Silvious at 301-845-6514 or jsilvious@yahoo.com.
 - Tuesday, October 28, 2014 (4th Tuesday): Berkeley County Parkinson's Support Group monthly meeting at 6:30 PM at the *Otterbein United Methodist Church of Martinsburg WV*. Contact Debi Corbin at 304-886-8594 for more information.
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- Thursday, November 6, 2014 (1st Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Dr. Stephen Ryan, Physical Therapist, is the featured speaker. Call Art at 240-625-2722 for information or directions.
 - Friday, November 7, 2014: Support Group Leaders Dinner and Meeting: BWI Airport Marriott, in Baltimore, MD. Details to come.
 - Saturday, November 8, 2014: Johns Hopkins Movement Disorders Symposium, BWI Airport Marriott, in Baltimore, MD. Call Bailey Vernon at 410-616-2811 for information and to register. Details to come.
 - Monday, November 17, 2014 (3rd Monday): Caregivers' Breakfast at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
 - Tuesday, November 18, 2014 (3rd Tuesday): Chambersburg PD Support Group Monthly Meeting at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or kathy.smith@embarqmail.com for information or directions.