

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

March 2014

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

Volume 4, Issue 3

[Visit us on Facebook](#)

This Month's Meeting

We had 42 attendees at our February meeting. A great turnout considering the weather.

Our speaker this month was **Dr. Padraic Keen**, a Resident Pharmacist at Meritus Health. He was accompanied by **Dr. Chris Virgilio** the Pharmacy Clinical Coordinator for Meritus. Padraic presented a good description of PD medications, a detailed description of the NPF Awareness in Care Kits, and he described the hospital generic policies regarding medications and gave us suggestions to overcome some of the standardization issues. He stressed that patients should make use of the Patient Advocates at the hospital and feel free to contact (or have staff contact) the hospital pharmacists for help.

Drs. Keen and Virgilio can be reached at 301-790-8904. Patient Advocates Fred Hirsch (301-790-8499) and Carolyn Carder (301-790-8662) are available for help.

I want to thank **Dick Naugle** for asking the blessing. **James Mattern** won the \$10 gift certificate to the Western Sizzlin Restaurant donated by **Paul Romsburg** and his family.

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KNOW SOMEONE WHO NEEDS A WALKER?



The Maugansville Ruritan Club has walkers for anyone who needs one. Before you buy a walker, give **Jay Stouffer** a call at 301-739-9221.

They also have a limited number of wheel chairs and hospital beds.

February 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, March 6, 2014, 11:45 AM

Hilary F. Lo, Commission on Aging

Highlights

[Ten Things for the Caregiver to Do \(Page 3\)](#)

[Fatigue and Parkinson's Disease \(Page 4\)](#)

[Managing PD Symposium \(Page 6\)](#)

Put this on your Calendar!
Our Picnics are scheduled for:
June 20th and September 12th.

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The Berkeley County Parkinson's
Support Group is having a seminar
on April 12th.

Free Registration.

More information
to come.



Upcoming Events

Future Meetings

March 6, Hilary F. Lo, Commission on Aging
April 3, Dr. Stephen Grill, Neurologist
May 1, Kylie Osman, Speech Therapy
June 5, Breakout Sessions
July 3, Bailey Vernon, JHM Health Educator
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

Educational and Other Activities

Caregivers' Breakfast:

Third Monday of every month, 8:30 AM at the Railroad Junction Family Restaurant. February's breakfast is the 17th. Call Art Guyer for information.

Continued on Page 2. Please let us know of any events you would like to see publicized.

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
Sharon Wilson, Facilitator, 304-258-0496
sharonjfk50@frontier.com
<http://www.walkrunmove.org/>

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

Chambersburg Parkinson's Support Group
Warren Leach, 717-264-2908
SKIPL815@AOL.COM

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.

We have established the 3rd Monday of every month as the morning for our Caregiver's Breakfast; so you can plan in advance. In January, **Mike Saterbak, Ecile Shaw, Barbara Harrell, Dave DeHaven, Doug DeHaven, Connie Kaiser, Sandy Phillips, and Art Guyer** enjoyed the Caregivers' Breakfast and discussed some of the aspects of the upcoming seminar. YES, COUNT THEM – EIGHT ATTENDEES!

This month, caregivers will meet for breakfast on February 17th, 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.

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Birthdays in February

Happy Birthday to 3 of our members who have February birthdays: **Doris Fearnow, Jamie Fleming, and Jay Stouffer.**

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



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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.

Medicare Policy Change

Effective, January 7, Medicare beneficiaries can no longer be denied coverage for physical, occupational, and speech-language therapy services solely for lack of improvement.

In 2011, a lawsuit was filed against the Center for Medicare and Medicaid Services (CMS) over a standard for Medicare coverage that discriminated against people with Parkinson's. The standard commonly referred to as the Improvement Standard, required Medicare beneficiaries to show improvement to continue physical, occupational, and speech-language therapy services. For a degenerative disease like Parkinson's, therapy is not a cure, but it is a treatment option that can improve quality of life and help maintain independence.

The lawsuit reached a favorable settlement in January 2013, and CMS was given one year to update its policy manual as well as develop and implement a nationwide education campaign for all who make Medicare determinations.

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Managing Parkinson's Disease: A Community Symposium

Planning is moving along for our April 4th symposium. Our caterer and the menu has been determined. As of this printing, **we are at about 40% of our capacity.** See [Page 6](#) for details of the agenda and speakers.

The Hospice of Washington County in Hagerstown, MD, is hosting our event. The registration fee of \$10 per individual (\$15 after March 14) includes lunch. A number of local businesses are making contributions for door prizes to be drawn during the lunch hour. If you can volunteer to hand out flyers, solicit contributions for door prizes, etc. please contact **Art Guyer.**

Upcoming Events (Cont. from Page 1)

Totem Pole Theater Trip: "Ring of Fire: The John Cash Musical"
July 2, 2014 3:00 PM
Contact Art for Discounted Tickets

Johns Hopkins Educational Seminars
(Registration is required for all):

Managing Parkinson's Disease: A Community Symposium: All day seminar at Hospice of Washington County, Hagerstown, MD. [See Page 6 for Details.](#)
April 4, 2014 9:00 AM – 4:00 PM

Parkinson's Disease 101: For recently diagnosed patients and family.
To Be Scheduled 5:00 PM – 8:30 PM

Parkinson's Disease 201: For patients diagnosed for at least 5 years, and family.
To Be Scheduled 5:00 PM – 8:30 PM

Deep Brain Stimulation: A session on the innovative technique to provide relief for people with Parkinson's Disease.
To Be Scheduled 6:00 PM – 7:30 PM

For more information on the JHU events, contact **Bailey Vernon** at 410-616-2811 or bvernon1@jhmi.edu.

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.



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Top Ten Things for Caregivers to Start Doing for the New Year (Caregivers.com)

1. Keep records of all medications and reactions: make notes about what works, what doesn't and when you informed the physician of any problems.
2. Keep records of all doctor appointments: the reason for the visit, the doctor's responses to our concerns, any procedures performed, etc.
3. Start or continue to maintain copies of medical records for your loved one, and for yourself, as well. These will be beneficial should a grievance arise or if there are questions about medical histories.
4. Plan for the unexpected: discuss plans and wishes of everyone involved in the caregiving family. Talk about final resting places and what arrangements your family will want.
5. Have an Advance Directive filled out and given to the primary physician and all relatives who may need the form.
6. Have a Last Will and Testament completed or updated: without a signed Will, the courts will decide how to distribute the possessions of your loved ones.
7. Keep a record of where all-important documents are kept. When an emergency or tragedy occurs, locating information should not be where we spend our thoughts and energies.
8. Record all monetary involvements: investments, resources creditors, debtors, business transactions, etc.
9. Have an insurance analysis done: is your home, life and health insurance still appropriate for your family's needs? What about the insurance policies for your loved ones? Do you all have enough coverage to take care of any eventuality? Do you have provisions for Long Term Care? For respite care? Is your house adequately covered given the state of the weather patterns?
10. Clean out the medicine chest. Look for expiration dates on all medicine, and check with your doctor about previous medications which will either be harmful with current prescriptions or which are no longer effective for your or your loved one. Not only will you save space, you might also save a life.

Did You Know?

Staying well hydrated is very important in Parkinson's disease.

Dehydration can lead to worsening of symptoms so always keep a water bottle close by and remember to keep drinking!



WHATEVER IT TAKES
to Beat Parkinson's

www.parkinson.org/whateverittakes

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Fatigue and Parkinson's Disease

Many people with Parkinson's disease (PD) experience fatigue. We do not know everything about this common symptom, but we do know that fatigue can have both mental and physical causes. In Parkinson's disease, the feeling of fatigue is hard to describe and even harder to measure. Fatigue can be caused by or made worse by slow movement, muscle stiffness, depression, changes in being able to move or sleep well, and even medications. It can also be experienced throughout the day or only when medications are wearing off.

- Fatigue Due to Akinesia - Akinesia, or trouble starting a movement, often feels like fatigue. A person with this symptom must move slowly and will find it hard to finish a task in a regular amount of time. Everyday tasks such as getting dressed can take a lot of effort.
 - *Helpful tip:* Keep track of times during the day when akinesia is better and medications are working well. Energy consuming tasks can then be done at these times when movement is easier.
- Muscle Fatigue - PD symptoms like muscle stiffness, cramping, tremor or shaking, and difficulty initiating a movement put stress on a person's muscles. To move with these symptoms, muscles have to work very hard and often against each other. With tremor, the constant shaking can quickly fatigue muscles. Muscles that do not move enough are not well-conditioned, and they can become reduced in size (atrophied). Loss of muscle strength decreases stamina and endurance. For many people, this decrease feels like fatigue.
 - *Helpful tip:* Anti-parkinson medications can be used to treat symptoms like tremor, which can cause fatigue. These medications must be carefully monitored to avoid a common side effect called dyskinesia (fidgety, involuntary movements), though, because dyskinesia can also cause fatigue. The only treatment available to keep muscles well-conditioned is a regular exercise program. People who have included exercise as a part of their daily routine have less fatigue!
- Fluctuations in Mobility - Many people with Parkinson's disease have fluctuations in their mobility throughout the day. Typically these fluctuations follow the dosing cycle. In other words, individuals with PD experience an increase in symptoms at the end of a dose. It is also common to have the best relief from symptoms in the morning because this is when most people feel well rested.
 - *Helpful tip:* Often, people try to get everything done in the morning when they feel well, but too much activity in the morning can lead to fatigue. Time your periods of activity for maximum mobility, but also pace yourself and allow for rest periods.
- Fatigue due to Depression - Depression is common in people with Parkinson's disease. It occurs in about 40% of the patients. Fatigue is a typical symptom of depression and is often reported as a lack of motivation or a loss of energy.
 - *Helpful tip:* Antidepressants are used to treat this problem. When successful, people begin to feel less tired and are more willing to participate fully in a day's activities.

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- **Fatigue due to Sleep Disturbance** - Parkinson's disease is often associated with sleep disturbance. Causes vary but may be due to sleep cycle changes, inability to get comfortable, or side effects of medications. Sleep disruption contributes to daytime sleepiness, and people often have a strong desire to nap throughout the day.
 - *Helpful tip:* A short nap after lunch is healthy and refreshing, but frequent naps throughout the day will only make sleeping at night more difficult. Sleep problems should be evaluated by your doctor because it is well-known that a poorly rested person will perform poorly during the day. It is also important to note that some medications used to treat sleep disturbance may cause daytime fatigue.
- **Fatigue due to Medications** - Dopamine agonists, such as Mirapex® and Requip®, can cause fatigue and daytime sleepiness.
 - *Helpful tip:* Reducing the medication may help; however, it can come at the cost of increased PD motor symptoms. Medications such as Provigil® and Ritalin® are being studied for combating fatigue in PD.

WORKING WITH YOUR CLINICIAN TO MANAGE FATIGUE:

It is clear that fatigue is a problem for many people with Parkinson's disease. To get help, a complete health history and physical exam is first necessary to rule out non-Parkinson causes. Sometimes problems not associated with PD, such as anemia, are found.

If you are experiencing fatigue, ask yourself the following questions and record them in a notebook. Then bring this information to your next doctor's appointment and share it with your doctor:

- When do I feel fatigued?
- How long do my feelings of fatigue last each day?
- Does my fatigue fluctuate with my symptoms?
- Does my fatigue fluctuate with the time that I take my medications?
- On a scale of one to ten, how fatigued am I in the morning, around noon, and in the afternoon?

The answers to these questions can help you and your doctor work together to identify possible causes of the fatigue you are experiencing. If necessary, Parkinson's medications can be adjusted.

Some Steps People Can Take to Avoid Fatigue:

- Eat well. Getting the right food is necessary for feeling strong.
- Participate in an exercise program with both aerobic (biking, swimming, walking, running) and stretching exercises.
- Practice good sleep habits! Establish a regular bedtime, avoid frequent napping or stimulation at bedtime, and decrease caffeine and alcohol intake.
- Keep mentally active. Boredom often leads to fatigue.
- Eat a lot of fiber and drink plenty of fluids to avoid constipation.
- Do more difficult daily tasks when movement is easier and medications are working well.
- Know your limitations and seek assistance when necessary. Forcing too many activities into one time period will cause fatigue.

www.parkinson.org

Cathi A. Thomas, R.N., M.S.
The Parkinson Handbook

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Managing Parkinson's Disease

An educational program for the community

Agenda

- 9:00 a.m. Registration
9:30 a.m. Opening Remarks
Art Guyer, Hagerstown Support Group Leader
9:45 a.m. Introduction to Parkinson's Disease
Becky Dunlop, RN, BSN, Johns Hopkins
10:45 a.m. Break
11:00 a.m. Parkinson's Disease Treatment Overview
Liana S. Rosenthal, MD, Johns Hopkins
12:00 p.m. Lunch
1:00 p.m. Parkinson's Community Support
Art Guyer, Hagerstown Support Group Leader
1:15 p.m. Speech and Swallowing
Danielle Walters, MS, CCC/SLP, Better Speech and Swallow
2:00 p.m. Break
2:15 p.m. Exercise and Physical Therapy
Stephen Ryan, PT, DPT, Ryan Physical Therapy
3:00 p.m. Your Parkinson's Disease Management Plan
Bailey Vernon, MPH, Johns Hopkins
3:45 p.m. Concluding Remarks
4:00 p.m. Program Concludes

Friday, April 4, 2014

9:00 a.m. – 4:00 p.m.

Hospice of

Washington County

747 Northern Avenue,
Hagerstown, MD 21742

Presented by:

Hagerstown Parkinson's Support Group

*Johns Hopkins Parkinson's Disease and
Movement Disorders Center*



Register by mailing this form to Art Guyer at 22215 Troy Lane, Hagerstown, MD 21742, calling 240-625-2722, or emailing aguyer42@myactv.net. Registration fee includes lunch. Checks should be made payable to JH PDMD Center.

___ Early Bird Registration before March 14, 2014
\$10 for an individual

___ Registration after March 14, 2014
\$15 for an individual

Name(s): _____

Address: _____

Phone: _____

Email: _____

Amount Enclosed: _____

Check No. _____