

# The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

## Monthly Newsletter

February 2014

Visit Our Website at:  
[www.fareshare.net/Parkinsons/](http://www.fareshare.net/Parkinsons/)

Volume 4, Issue 2

[Visit us on Facebook](#)

### This Month's Meeting

We had 44 attendees at our January meeting. It cleared out pretty quickly when the snow started to come down hard.

Our speaker was Attorney Michael Day who spoke on Elder Law issues that we must face. His style, delivery, and information were great and many members indicated they were impressed with the presentation on Medicaid Asset Protection. He covered a number of areas where misinformation can be gotten from misinformed sources. He also went into a little detail about what assets can be protected and which cannot if an individual has to go into a long-term care facility.

This presentation was a shortened version of the one he provides at monthly seminars in Western Maryland. Seminars are held in Hagerstown and Frederick in alternating months. They come highly recommended as a starting point before you see an attorney about things like asset protection. Anyone interested should call his office to register for a seminar and the free dinner that is provided. His contact information is:

Hagerstown: 301-739-6820  
Frederick: 301-228-2960  
Cumberland: 301-724-4713

Email: [info@mikedaylaw.com](mailto:info@mikedaylaw.com)

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I want to thank Ecile Shaw for asking the blessing. Harold Burgesser won the \$10 gift certificate to the Western Sizzlin Restaurant donated by Paul Romsburg and his family.

### January 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, February 6, 2014, 11:45 AM

Padraic Keen, Meritus Pharmacist

#### Highlights

[Delivering Levodopa \(Page 3\)](#)  
[Enhancing Hand Coordination \(Page 4\)](#)  
[The Right Support Group \(Page 5\)](#)  
[Managing PD Symposium \(Page 6\)](#)

**Don't forget to register for our April 4<sup>th</sup> seminar, "Managing Parkinson's Disease: An educational program for the community. The staff of John Hopkins has done a great job putting this together and The Hospice of Washington County is providing the venue. See page 6.**

**Hope to see you there.**

### Upcoming Events

#### Future Meetings

February 6, Padraic Keen, Pharmacist, Meritus  
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. January's breakfast is the 20<sup>th</sup>. 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](mailto:danicasgma@aol.com)

Winchester Area Parkinson's Support Group  
Sharon Wilson, Facilitator, 304-258-0496  
[sharonjfk50@frontier.com](mailto:sharonjfk50@frontier.com)  
<http://www.walkrunmove.org/>

Cumberland Parkinson's Support Group  
Shirley McKinney, Facilitator, 301-729-1427  
[sjmckinney@atlanticbb.net](mailto:sjmckinney@atlanticbb.net)

Chambersburg Parkinson's Support Group  
Warren Leach, 717-264-2908  
[SKIPL815@AOL.COM](mailto: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](mailto: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 3<sup>rd</sup> Monday of every month as the morning for our Caregiver's Breakfast; that way you can plan in advance. In December, **Mike Saterbak, Ecile Shaw, Barbara Harrell, Peg Hayzlett, and Art Guyer** enjoyed the Caregivers' Breakfast and discussed some of the aspects of the upcoming seminar we are planning for April 4<sup>th</sup>.

This month, caregivers will meet for breakfast on January 20th, at the Railroad Junction Family Restaurant, at 8:30 AM. The restaurant is located at 301 S. Burhans Blvd E, still 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 December

Happy Birthday to 7 of our members who have January birthdays: **Don Phillips, Pat Donnelly, Betty Stouffer, Kathryn Miller, Curtis Fuller, Dean Cook and Paul Embly.**

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!



### Card Sharks?

Do you like to play cards or would you just like to get away for a couple of hours? Some of us have been playing about once a month. In December we played at the home of **Jerry & Barb Harrell**. We'd like to get some more players so we could have two games going when we play. We can provide transportation if necessary. **Dave DeHaven** is our point person on this activity. See him at a meeting or call him at 301-582-2815.

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### Managing Parkinson's Disease: A Community Symposium

Thanks to **Bailey Vernon** from Johns Hopkins Parkinson's Disease and Movement Disorders Center, the agenda for our "Managing Parkinson's Disease: An educational program for the community" has been finalized. [See Page 6](#) for details of the agenda and speakers.

We have begun to accept registrations for the Friday, April 4, 2014, event which will run from 9:00 AM to 4:00 PM. The Hospice of Washington County at 747 Northern Avenue in Hagerstown, MD, has agreed to host our seminar at no cost to us. Major companies TEVA and Medtronic have made major donations to help offset other costs of the event. The registration fee of \$10 per individual (\$15 after March 14, 2014) includes snacks, drinks, and lunch. A number of local businesses are making contributions for door prizes to be drawn during the lunch hour.

Flyers for the event are now ready for distribution. If you can volunteer to hand out flyers, or solicit contributions for door prizes, please contact **Art Guyer**.

### Upcoming Events (Cont. from Page 1)

#### 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 these JHU events, contact **Bailey Vernon** at 410-616-2811 or [bvernon1@jhmi.edu](mailto: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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### 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.

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### Delivering Levodopa

The key to success: finding better ways to deliver, and then maintain, therapeutic levels of levodopa in the bloodstream.

Since it was first prescribed for Parkinson's in the late 1960s, levodopa has been the so-called gold standard therapy for PD. Today, people with Parkinson's take the drug in conjunction with carbidopa, a therapy meant to prolong the life of levodopa in the bloodstream, and, in turn, its therapeutic effect. But it is not perfect.

The good news is, the past few years in PD research has returned significant and positive clinical study results for new therapies that have been shown to lessen on/off periods in people with PD.



### Inhaled Relief From On/Off Periods

This spring biotech Civitas Therapeutics announced positive clinical trial results for their inhaled formulation of levodopa, called CVT-301. The Phase 2a study showed that, when administered to patients in an off state, it provided a rapid improvement in motor function.

CVT-301 is designed to work as a "rescue drug" to be taken in conjunction with the traditional pill form of levodopa/carbidopa. The idea is that patients would be able to self-medicate by taking a puff from an inhaler when they feel an off period coming on. This puff would bring the amount of levodopa in the bloodstream back to a level that provides a therapeutic effect. The device, similar to an asthma inhaler, is small enough to fit in a jacket pocket or a purse. And it works fast — in some cases, in just five minutes. Here's why: any drug delivered via the lungs will get into the bloodstream faster.

Phase 3 studies are expected to begin in the second half of 2014. Upon completion, the company expects to file for FDA approval — with the goal of having CVT-301 available to patients soon thereafter.

### Intestinal Gel

Research has progressed for a levodopa/carbidopa intestinal gel (LCIG) delivered into the small intestine via a pump attached to the body during waking hours. In 2012, AbbVie (formerly Abbott) announced positive Phase 3 clinical results that showed the pump could reduce off periods by as much as four hours per day, while on time without dyskinesia increased by more than four hours. LCIG is already available in Europe under the brand name Duodopa.

### Patch

A levodopa/carbidopa "pump patch" from Israeli drug maker Neuroderm is a device no larger than a credit card, made up of a reservoir where the drug is stored, and a series of painless micro-needles, which pump the therapy under the skin and into the bloodstream continuously. The company shared positive Phase 1 results last spring and a planned Phase 2 study to better understand its efficacy in the works.

### Improved Pill Forms

In 2012, Intec Pharmaceuticals announced positive results from a small proof of concept study into an "accordion pill" formulation of levodopa. The pill is compressed into capsule form, then opens slowly in the stomach, providing a more continuous release of levodopa into the body.

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Posted by [Nate Herpich](#), November 21, 2013, Michael J. Fox Website

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National Parkinson's Foundation

### Enhancing Hand Coordination

We use our hands throughout the day in all activities. Active people with Parkinson's may notice changes in the ease in which they perform hand and finger motions. This change may be due to slow movement, tremor, feelings of stiffness, and/or loss of automatic movement patterns. This may lead to extra time and frustration when performing tasks. The following tips can enhance hand coordination:

- Focus on the task at hand—divided attention often makes doing even basic, routine tasks more difficult.
- Slow down. Rushing through tasks can make them more difficult to perform.
- Exercise hands and fingers regularly. Simple stretches or a hand exerciser keeps hands and fingers flexible. Playing musical instruments, cards, or board games may also help.
- Using a computer keyboard regularly helps keep hands and fingers working well. Explore adaptations for computer hardware/software if keyboarding is difficult.
- Gardening, knitting, and other hobbies provide fun and stimulating hand exercise.
- Using toothbrushes, hairbrushes, silverware, and writing tools with larger handles may help make tasks easier to perform.
- Stabilize arms or elbows by resting them on a table or against your body. This decreases effects of arm and hand tremor.
- Involve both hands in tasks to ensure continued use and flexibility. Avoid the tendency of favoring one hand over another to complete tasks.
- Take “mini-breaks” to rest if needed.
- Schedule tasks that require greater hand control for times when you are well rested and medications are working well.
- Stress can contribute to slowness, tremor, and/or stiffness. Avoid frustration by allowing extra time and adequate rest between activities.

Consult an occupational therapist for evaluation and recommendations to improve hand coordination. Exercises, compensation strategies, or adaptive tools may help with tasks you find difficult to perform.

### Did You Know?

Stress of any kind can make your Parkinson's symptoms temporarily worse.

Relaxation techniques are helpful to manage stress in a positive way.



**WHATEVER IT TAKES**  
to Beat Parkinson's

[www.parkinson.org/whateverittakes](http://www.parkinson.org/whateverittakes)

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### The Right Support Group

Support Groups can provide great comfort to family caregivers but finding the right one depends on many factors. Here are some things to think about when looking for a group.

#### What makes a support group successful?

- A safe haven for sharing true feelings
- A place to make new friends
- Information about resources and coping mechanisms
- Advice on what lies ahead
- Help in dealing with family members

#### Why are support groups so important?

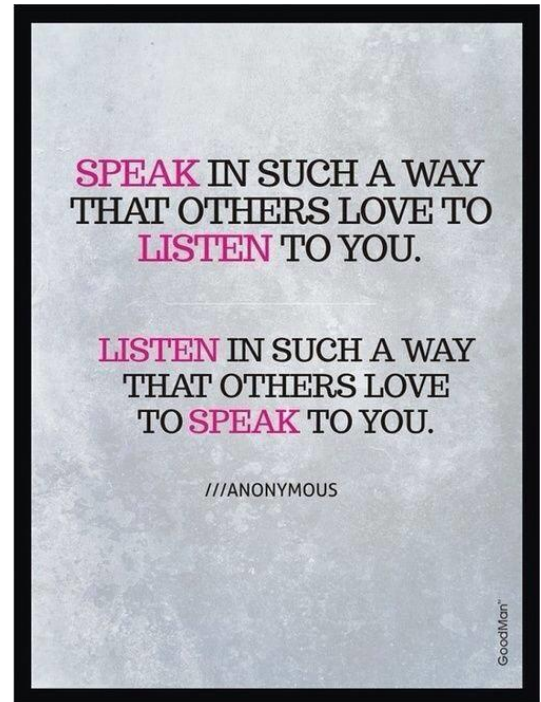
- A caring atmosphere with trust between group members
- A clear structure and purpose
- Agreement on group rules, including confidentiality
- A good facilitator

#### Where to find a group

- The social work department of hospitals
- Adult day care centers
- Voluntary orgs that deal with your care recipient's condition
- Area Agencies on Aging
- Your faith community

#### Questions to Ask

- Who sponsors/runs the group?
- Who is the facilitator?
- What is its organizing principle?
- What is the makeup of the group?



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## *Do I need a support group?*

Many people find that support groups are tremendously effective in helping them cope with the day-to-day realities of having Parkinson's disease. Groups come in different formats — from large, formal meetings to smaller "living-room" get-togethers — and you probably won't be equally comfortable with or get the same benefit from all. If you don't like the first group you find, it's worth looking for one that suits you better. If you can't find any you like in your area, consider starting one. If you are unsatisfied with the available options, it is likely that you're not the only one feeling that way.

**Michael J. Fox Organization**

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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](mailto: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. \_\_\_\_\_