

# The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

## Monthly Newsletter

February 2015

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

Volume 5, Issue 2

[Visit us on Facebook](#)

### This Month's Meeting

We had **45 attendees** at our January 8th meeting, including **7 new members**. It was a wonderful turnout given the cold weather and how much sickness is going on in our area. And 7 new folks is a great way to start the New Year. Please come back often.

Dr. Kelly Mills from the Johns Hopkins Parkinson's Disease and Movement Disorders Center was our featured speaker. He is from the Thurmont area originally and graduated from the university of Maryland School of Medicine. He completed his education and training at the University of California and is a specialist in movement disorders. Dr. Mills discussed deep brain stimulation, the process from start to finish, and in particular how evaluations for candidates are handled. He did an outstanding job answering questions during his presentation and while he joined us for lunch.

One of our new members, **Larry Miley**, won the \$10 gift certificate to the Western Sizzlin' Restaurant donated by Paul Romsburg and his family.

We want to thank **Ecile Shaw** for asking the blessing.

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### Do You Shop at Amazon?

Sign in at [www.smile.amazon.com](http://www.smile.amazon.com) and scroll down to the bottom of the page; under "Get to Know Us," click on "About AmazonSmile and follow the directions. Now Amazon will contribute a percentage of your purchases to the Maryland Association for Parkinson's Support."

### 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, February 5, 2015, 11:45 AM**

In February our speaker will be  
**Dietician Irene Plessinger** from  
the Chambersburg Area.

#### Newsletter Highlights

New Area PD Support Group ([Page 3](#))

Levodopa Pump ([Page 4](#))

Caring in Parkinson's ([Page 5](#))

Questionnaire ([Page 6](#))

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

### Attend a Support Group Meeting



**Picnics: June 19 and September 18, 2015**  
**More to Come!**

[Check out the new Parkinson's Events Calendar On-Line.](#)

### Future Meetings

February 5, Irene Plessinger, Dietician  
March 5, Stephanie Mahan, LSVT/BIG  
April 2, Arita McCoy, RN, Johns Hopkins  
May 7, Lori Markland, Assistive Technology  
June 4, Breakout Sessions  
**July 9**, Candice Valencia, Senior Exercises  
August 6, Becky Dunlop, JHU  
Sept. 3, Richard Lewellen, Music Therapist  
October 1, Dr. Joseph Savitt, Neurologist  
Nov. 5, Amanda Distefano, WCHD, Falls  
December 3, Breakout Sessions

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

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#### 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  
Cheryl Reames, Facilitator, 540-662-4632  
[winchesterparkinson@gmail.com](mailto:winchesterparkinson@gmail.com)  
[Facebook.com/winchesterPDsupport](https://www.facebook.com/winchesterPDsupport)

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, Facilitator, 717-264-2908  
[skipl815@aol.com](mailto:skipl815@aol.com)

Frederick Parkinson's Support Group  
John Kraft and Janet Silvious, Facilitators  
301-845-6514  
[janet@fifpdsg.org](mailto:janet@fifpdsg.org)  
[www.fifpdsg.org](http://www.fifpdsg.org)

Frederick Parkinson's Disease Early Onset or Newly Diagnosed Community Support Group  
Deb Bergstrom, Facilitator, 301-712-5381 or  
[dfbergstrom@comcast.net](mailto:dfbergstrom@comcast.net)

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

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month. In December, **Carol Gaines, Barbara Harrell, Dave DeHaven, Mike Saterbak, Ecile Shaw and Art Guyer** enjoyed the Caregivers' Breakfast.

This month, caregivers will meet for breakfast on January 19th, 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. If you need transportation, let us know and we will take care of it.

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### New Support Group

A new group, the Frederick Parkinson's Disease Early Onset or Newly Diagnosed Community Support Group, is kicking off their initial meeting on Saturday, January 17th, from 2:30 to 4:30 PM at the C. Burr Artz Library. See [page 3](#) for details.

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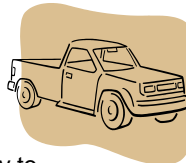
Keep the smile, leave the tear,  
Hold the laugh, leave the pain,  
Think of joy, forget the fear,  
Be joyous, cause it's a New Year!

## Happy New Year!

### Need Transportation?

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.



### Wellness Ambassador Announced



The Western Maryland Health System's Wellness Ambassador for the month is Shirley McKinney. Shirley was diagnosed with Parkinson's disease 10

years ago. She recognized a need for a Parkinson's support group in the Cumberland area, so she took it upon herself to start one. The support group has been meeting monthly for about two and a half years. Shirley goes out of her way to have good speakers and activities and often calls on WMHS Professionals to share their expertise.

Shirley is a retired RN, surgical nurse at WMHS and now serves with her husband, as a front desk volunteer. She has also served as patient advocate.

She is an active member of Grace Memorial Community Church, serving on the Missions Committee and assisting with a number of projects. Shirley has been singing in the band "Summer Wind" for many years and they now are providing inspirational music for nursing homes and the community.

Thank you Shirley for all that you do! You are an inspiration, role model and wellness champion for the community.

### Cards

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game on January 16<sup>th</sup> at Peg Hayzlett's home in Hagerstown. We really need some more players, men and women.

### PD Group Bowling

On Thursday, January 15th we meet again for duckpin bowling at Southside Bowls on Virginia Avenue in Hagerstown. The alleys will be set up for those who have difficulty moving, lifting or even walking.

Join us for the fun and the exercise! Call **Dave DeHaven** at 301-582-2815 for more information and directions.

### Birthdays in January

Happy Birthday to our members who have January birthdays: **Paul Kaiser, Don Phillips, Pat Donnelly, Betty Stouffer, Kathryn Miller, Curtis Fuller, Dean Cook, William Wilhide, Linda McSweyn, Paul Embly, and Betty Gladhill.**

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 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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## Frederick County, Maryland Parkinson's Disease Early Onset or Newly Diagnosed Community Support Group

**Kick-Off Meeting**  
**Saturday, January 17, 2015**  
**2:30 p.m. - 4:30 p.m.**  
**C. Burr Artz Library, Room 100**  
**110 E Patrick Street**  
**Frederick, MD 21701**

**Contact: Deb Bergstrom, [dfbergstrom@comcast.net](mailto:dfbergstrom@comcast.net) or 301-712-5381**

**This is a free event. Pre-registration is not required, but encouraged.**  
**Register at <http://goo.gl/g5HKAo>.**

Please join us for the first community meeting for individuals newly diagnosed with Parkinson's disease or diagnosed at a younger age that live in Frederick, Maryland or surrounding communities. Family members and friends are invited to attend. This is a great place to start if you are hesitant about participating in a support group!

These meetings will be an opportunity to connect with other individuals, learn of valuable community resources, and reliable information about Parkinson's disease. The kick-off meeting will be an opportunity to provide your input on the group and also ask questions and express your needs. There will be light refreshments.

### **Community Partners:**

*Columbia Parkinson's Disease Early Onset / Newly Diagnosed Support Group*

*Frederick County Department on Aging*

*Friends in Frederick Parkinson's Disease Support Group*

*Hagerstown Parkinson's Support Group*

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

*Maryland Association for Parkinson's Support, Inc.*

*University of Maryland Parkinson's Disease and Movement Disorders Center*

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### Levodopa Pump Shows Promising Phase II Results

Michael J. Fox Foundation

Posted by [Maggie McGuire](#), December 30, 2014

**Neuroderm is testing a pump system to deliver levodopa/carbidopa. Image via Neuroderm**



A belt-worn pump that delivers levodopa/carbidopa continuously under the skin may help alleviate the motor fluctuations associated with traditional, oral therapy.

Israeli company Neuroderm recently announced that it saw clinically significant levels of levodopa in plasma in a Phase II trial of its pump system to deliver a liquid form of levodopa/carbidopa. The Michael J. Fox Foundation funded this study.

Neuroderm is also testing a pump-patch product to deliver the drugs under the skin. That product resembles a nicotine patch with microneedles to inject the drug. The pump from the company's latest study is similar to an insulin pump for diabetes.

"Maintaining consistent levodopa concentrations has been the most significant hurdle in Parkinson's disease therapy," said Sheila Oren, MD, NeuroDerm's Vice President of Clinical and Regulatory Affairs and principal investigator on the study.

The current gold standard, levodopa is a compound converted to dopamine in the brain, replacing the neurotransmitter that controls movement and that is lost in Parkinson's disease. The oral form of levodopa is absorbed into the bloodstream only in a small part of the intestine then must travel to the brain. Carbidopa helps avoid the breakdown of levodopa along its journey.

Over time, levodopa loses its efficacy and symptoms return before it's time for another medication dose. Patients can't take an unlimited amount of levodopa because too much causes debilitating side effects such as involuntary movements called dyskinesia.

"These results add to the growing body of clinical data confirming our thesis that continuous, subcutaneous delivery of levodopa/carbidopa leads to more consistent therapy, which we expect to have a dramatic effect on patient outcomes and quality of life," said Oded S. Lieberman, PhD, CEO of NeuroDerm.

**Comments from the National Parkinson's Foundation:** The pump is approved and available in 43 countries. The United States has lagged behind the world in adopting this new approach to Parkinson's disease therapy. However, in defense of the U.S.A. and the FDA, prior to the publication of the current pump trial, all previous results were based on uncontrolled evidence. The benefits of the pump have been clearly demonstrated. In this population of fluctuating patients, the data would suggest that the pump out-performs standard medical therapy. The study did not enroll patients with severe dyskinesia, and it is unclear how the continuous infusion pump will perform in more severe and more disabled Parkinson's disease patients.

One of the major drawbacks to the pump approach is the need for a small feeding tube. These types of tubes can serve as points for infections and other complications, and in the current study, device complications were present in 89% of subjects. The complications were addressable in most cases, and were reported as lower than in previous pump trials.

Patients should be aware that the current version of the pump requires wearing an external device, and it also requires changing a dopamine cassette once or twice a day. The pumps require continuous maintenance and programming by a qualified professional. The tube connected to the stomach also requires constant monitoring for infection.

If the continuous infusion approach receives FDA approval one important step will be to compare its effectiveness to that of deep brain stimulation therapy (DBS). Patient selection for pumps versus DBS will be an immediate and critical unmet need. One question will be whether the pump technology can help debilitated patients with and without cognitive dysfunction who may be excluded from DBS.

Patients should be aware that pumps are powerful symptomatic therapies, but not cures; and in most cases the continuous infusion pump will not address the dopamine resistant symptoms of walking, talking, and thinking. Pumps have not been shown to delay disease progression. The good news for the Parkinson's disease community is that for a subset of patients a "pill free existence" may be on the horizon.

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## Heads Up, Caregivers!

### Coping Tips for Caregivers of Those with Parkinson's Disease

WebMD Parkinson's Disease Health Center

As a caregiver of someone with Parkinson's disease, you have a lot to do:

- You help maintain the quality of life for your loved one.
- You educate yourself about symptoms, treatments, and the progression of the disease.
- You keep track of appointments with the doctor, medication schedules, and exercise.
- You offer the love and support necessary to meet the challenges of Parkinson's disease.

The role you have taken on is not an easy one. These tips offer some guidance on how you can help your loved one.

- **Take time for yourself.** Make sure you have time to relax. If necessary, enlist the help of other family members or even hire someone to assist you in providing care.
- **Learn as much as you can about your loved one's disease.** That way you'll understand what changes to expect in your loved one's behavior or symptoms and how you can best help when those changes occur.
- **Let your loved one participate.** Don't try to do everything for your loved one. Allow him or her the time to complete daily activities on his or her own, such as dressing.
- **Consult your loved one about his or her family affairs.** Although it's not easy to discuss these topics, you should be informed of your loved one's wishes regarding a living will, durable power of attorney, and do-not-resuscitate (DNR) order.
- **Set realistic goals for yourself and your loved one.** Don't attempt to do everything. By setting attainable goals, you are setting everyone up for success rather than disappointment.
- **Do not put your life on hold.** Continue to meet with friends, participate in hobbies or groups, and maintain a schedule as normal as possible. You will not only feel more energized, you will be less likely to feel resentful.
- **Have someone you can talk to.** You are there to listen to and support your loved one, but you also need a support person. Talk openly and honestly with a friend or family member. If that's not possible, join a support group. Understanding you are not alone and someone else is in a similar situation helps you to feel nurtured.

#### Challenges You as a Caregiver Are Likely to Face

There are challenges that a person with Parkinson's disease confronts. First, the disease can vary from day to day. There will be times when he or she can function almost normally and then other times when he or she will be very dependent. This is a natural part of the disease. But it can make a caregiver feel that the person is being unnecessarily demanding or manipulative. Keep in mind that Parkinson's is unpredictable and each day can pose new challenges for you and your loved one.

Also, keep in mind that Parkinson's is a progressive disorder. While medications and surgery can provide significant relief of symptoms, they do not stop the progression of the disease.

[Continued on Page 6]



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[Continued from Page 5]

Depression is also very much a part of the disease. It is important to recognize the signs and symptoms of depression so you can help your loved one seek treatment promptly. And, if you are feeling depressed and having trouble coping, it's just as important to get care for yourself.

### Communicating With Your Loved One

Parkinson's disease can make verbal communication very difficult for your loved one. That can get in the way of your ability to care for his or her needs. Here are some ways that can help you better understand your loved one.

- Talk to your loved one face-to-face. Look at him or her as he or she is speaking.
- In the case of advanced disease, ask questions that your loved one can answer "yes" or "no."
- Repeat the part of the sentence that you understood. (For example, "You want me to go upstairs and get the what?")
- Ask your loved one to repeat what he or she has said, or ask him or her to speak slower or spell out the words that you did not understand.

### Questionnaire

To date, only two members have submitted the following questionnaire form with suggestions for our group. This is your opportunity to have some input into the future of the Hagerstown Parkinson's Support Group. Please fill it out and send it to me or one of the board members.

**Help Improve Your Support Group: Complete this Form and Return it to a Board Member or Art Guyer**

Approximately how many meetings did you attend in 2014? \_\_\_\_\_

What can we do differently to increase your participation? \_\_\_\_\_

\_\_\_\_\_

What can we do to provide better support to our members? \_\_\_\_\_

\_\_\_\_\_

Please list any suggestions for speakers or topics we can address in 2016? \_\_\_\_\_

\_\_\_\_\_

Would you like to volunteer to help us keep our group going? Preferences? \_\_\_\_\_

Any other comments you would like to make? \_\_\_\_\_

\_\_\_\_\_



**Are you interested in participating in a Dancing for PD Exercise Program? This can be done in a chair or standing. [Hugh McSweyn \(717-401-0692\)](tel:717-401-0692) and [Peg Hayzlett \(301-791-0836\)](tel:301-791-0836) are trying to put together a small group of people for this activity. Please contact either of them if you might like to get involved**

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### Reminders of upcoming events as of Friday, January 09, 2015

#### 2015

- Friday, January 9, 2015 (1<sup>st</sup> Friday): Cumberland PD Support Group Monthly Meeting at Grace Memorial Community Church, Cumberland, MD at 4:00 PM. Becky Dunlap from Johns Hopkins is the featured speaker. Contact Shirley McKinney for more information and directions at 301-729-1427 or [sjmckinney@atlanticbb.net](mailto:sjmckinney@atlanticbb.net).
  - Tuesday, January 13, 2015 (2<sup>nd</sup> 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. Breakout Sessions! Contact Cheryl Reames for more information at 540-662-4632 or [cwreames@gmail.com](mailto:cwreames@gmail.com).
  - Thursday, January 15, 2015: HPSG Bowling at Southside Bowl, 17325 Virginia Ave, Hagerstown, MD, at 1:00 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
  - Friday, January 16, 2015: HPSG Cards at Peg Hayzlett's home at 1:00 PM, if we have enough players. Call Dave DeHaven at 301-582-2815 for information or directions.
  - Saturday, January 17, 2015 (3<sup>rd</sup> Saturday): Frederick Parkinson's Disease Early Onset or Newly Diagnosed Community PD Initial Meeting, Room 100 at the C. Burr Artz Library, 110 E. Patrick Street, Frederick, MD at 2:30 PM. For information about this kickoff meeting call Deb Bergstrom at 301-712-5381.
  - Monday, January 19, 2015 (3<sup>rd</sup> 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.
  - Wednesday, January 21, 2015 (3<sup>rd</sup> Wednesday): "Friends in Frederick" PD Support Group monthly meeting at 1:00 PM. Held at Mount Pleasant Ruritan Club in Walkersville, MD. Contact Janet Silvius at 301-845-6514 or [jsilvius@yahoo.com](mailto:jsilvius@yahoo.com).
  - Saturday, January 24, 2015: Four-State Alliance for Parkinson's Support Meeting for **GROUP LEADERS AND REPRESENTATIVES ONLY** at 11:00 AM to 3:00 PM. Meeting held at the Western Sizzlin' Restaurant in Hagerstown, MD. Call Art at 240-625-2722 for information or directions.
  - Wednesday, January 28, 2015 (4<sup>th</sup> Wednesday): 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, February 5, 2015 (1<sup>st</sup> Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Speaker: Irene Plessinger, dietician. Call Art at 240-625-2722 for information or directions.
  - Friday, February 6 2015 (1<sup>st</sup> Friday): Cumberland PD Support Group Monthly Meeting at Grace Memorial Community Church, Cumberland, MD at 4:00 PM. Contact Shirley McKinney for more information and directions at 301-729-1427 or [sjmckinney@atlanticbb.net](mailto:sjmckinney@atlanticbb.net). Kierstin Stevenson a physical therapist will be the speaker.
  - Tuesday, February 10, 2015 (2<sup>nd</sup> 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. Contact Cheryl Reames for more information at 540-662-4632 or [cwreames@gmail.com](mailto:cwreames@gmail.com).
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  - Wednesday, February 18, 2015 (3<sup>rd</sup> Wednesday): "Friends in Frederick" PD Support Group monthly meeting at 1:00 PM. Held at Mount Pleasant Ruritan Club in Walkersville, MD. Contact Janet Silvius at 301-845-6514 or [jsilvius@yahoo.com](mailto:jsilvius@yahoo.com).
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- Friday, February 20, 2015: HPSG Cards at TBD at 1:00 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
- Wednesday, February 25, 2015 (4<sup>th</sup> Wednesday): 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, March 5, 2015 (1<sup>st</sup> Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Speaker: Stephanie Mahan, PT, LSVT/BIG Clinician. Call Art at 240-625-2722 for information or directions.
- Friday, March 6 2015 (1<sup>st</sup> Friday): Cumberland PD Support Group Monthly Meeting at Grace Memorial Community Church, Cumberland, MD at 4:00 PM. Contact Shirley McKinney for more information and directions at 301-729-1427 or [sjmckinney@atlanticbb.net](mailto:sjmckinney@atlanticbb.net). Video: "You are Not Alone".
- Tuesday, March 10, 2015 (2<sup>nd</sup> 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. Contact Cheryl Reames for more information at 540-662-4632 or [cwreames@gmail.com](mailto:cwreames@gmail.com).
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