

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

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

Volume 5, Issue 1

[Visit us on Facebook](#)

This Month's Meeting

We had 36 attendees at the December 4 meeting, at which we broke into groups by caregivers and persons with Parkinson's. Both groups had good discussions and as usual I had to call time so we could continue with the rest of the meeting and lunch.

Following the lively discussion sessions, gifts were exchanged while **David Fleming** played seasonal music on his harmonica. Thanks Dave.

Betty Martin won the \$10 gift certificate to the Western Sizzlin' Restaurant donated by **Paul Romsburg** and his family. And **Charles "Eugene" Martin** took home the miniature Christmas tree donated by **Doris Guyer**.

I want to thank **Ecile Shaw** for asking the blessing and everyone for the moment of silence for our deceased members.

Also, thanks to the attendees who left generous gratuities for the staff. It was a very nice gesture and will help make their Christmas more enjoyable.



December 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, January 8, 2014, 11:45 AM

In January our speaker will be **Dr. Kelly Mills**, a neurologist from the Johns Hopkins Parkinson's and Movement Disorders Center.

Highlights

Community Service Awards (Page 3)
Patient Advocate Program (Page 4)
Message from Art Guyer (Bottom Page 4)
Caring in Parkinson's (Page 5)
Feedback and New PD Therapies (Page 6)
Detailed Event Listing (Pages 7 & 8)

Attend a Support Group Meeting



Do You Shop at Amazon?

Sign in at 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."

Upcoming Events

Future Meetings

2015

January 8, Dr. Kelly Mills, Neurologist, Hopkins Parkinson's and Movement Disorder Center
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

See [pages 7 and 8](#) for more events.

[Parkinson's Events Calendar On-Line.](#)

Other Local Support Group Contacts

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

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

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

Chambersburg Parkinson's Support Group
Warren Leach, Facilitator, 717-264-2908
skipl815@aol.com

Frederick Parkinson's 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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Monthly Newsletter

January 2015

Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3rd Monday of every month. In November, **Norma Craver, Carol Gaines, Barbara Harrell, Dave DeHaven, Mike Saterbak and Art Guyer** enjoyed the Caregivers' Breakfast.

This month, caregivers will meet for breakfast on December 15th, 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.

Christmas Tree

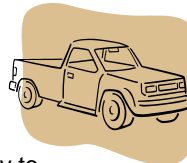
Dave and Patsy DeHaven did a beautiful job decorating our little Christmas tree. Thanks for your efforts.



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.



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Members Who Have Passed

David "Doc" Burrows

David Burrows died on November 3 at the Chambersburg Hospital, according to his wife Jane. She will appreciate your thoughts and prayers.



"Dick" Masters



On November 14 long-time support group member, Dick Masters, passed away. Please keep

his wife, Anita, and their family in your thoughts and prayers.

Also, late in November **Nancy Starliper** and **Clyde Fearnow** passed away. Please keep their families in mind also.

Cards

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game. We really need some more players, men and women.

PD Group Bowling

On Thursday, November 13rd we met again for duckpin bowling at Southside Bowls on Virginia Avenue in Hagerstown. The alleys were set up for those who have difficulty moving, lifting or even walking.

We will not be bowling in December, but will start again in January. Join us for the fun and the exercise! Call **Dave DeHaven** at 301-582-2815 for more information and directions.

Birthdays in December

Happy Birthday to our members who have December birthdays: **Kathy Ashway, Linda Embly, David Fleming, Timothy Minter.**

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.

Please have a safe holiday. And take care of each other!

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Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

Community Service Recognition

At our support group meeting on December 4, we presented a plaque to Paul Romsburg and his family in recognition of their contributions to persons with Parkinson's disease in Hagerstown and the four-state area. Two years ago the Romsburg's quickly agreed to host our meetings when we were no longer able to meet at the prior location. They have graciously provided for all of our needs, made donations for door prizes, purchased equipment, and continually seek ways to support our group. Their generosity is one of the reasons we have been able to continue growing our group and enjoying our time together. Thanks to them all; they have proudly hung the award just inside the entrance area. Look for it and when you get a chance thank everyone there.

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Becky Dunlop Award for Excellence in Parkinson's Community Outreach

The Maryland Association for Parkinson's Support proudly announced the establishment of an award for excellence in Parkinson's public outreach. This award has been created to honor the breadth, quality, innovation and diversity of activities provided to the Parkinson's community by Becky Dunlop. Those who have had the opportunity to work with Becky understand what a remarkable individual she is and what she has accomplished.

Becky Dunlop was presented this award, which will bear her name permanently, on Saturday, November 8, 2014, at the Movement Disorders Symposium in Baltimore, MD. Stories, comments, letters, cards and thoughts about Becky were assembled into a book which helped witness her impact on the Parkinson's community. It was also presented to her among cheers and a standing ovation.

If you would like to make a donation, this money will be used at the discretion of Becky Dunlop with the MAPS organization to provide funding for existing or newly developing programs to support the Parkinson's community.

To make a tax deductible contribution, please mail a check to:

Maryland Association for Parkinson Support, Inc.
PO Box 450
Brooklandville, MD 21022

OR donate online: <http://marylandparkinsonsupport.org/donate>

Please indicate your donation is in support of the **Becky Dunlop Award for Excellence in Parkinson's Outreach**. This can be indicated by a comment on your check or electronically. If you have any questions or concerns, please feel free to contact, Deb Bergstrom, at DFBergstrom@Comcast.net or by phone at 301-712-5381.

To learn more about MAPS, call 443-470-3223 or visit www.marylandparkinsonsupport.org.



(L-R) Deb Bergstrom, Becky Dunlop, Todd Hebb
(Photo by Arthur Rosenbaum)

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Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

AbbVie Patient Advocate Program Overview

The AbbVie Parkinson's Disease Advocate program is a no-cost program available to patients diagnosed with Parkinson's disease (PD) and their caregiver's. Whether you are newly diagnosed or have been living with PD for many years, a PD Advocate can help you learn more about your PD, how to find resources to help you live with the disease and identify a team of healthcare professionals who help you manage your disease progression.

An AbbVie Parkinson's Disease Advocate can:

- Educate you about PD and what you might expect during your journey.
- Support you as you deal with your concerns.
- Prepare you for meaningful conversations with your doctor.
- Help you identify resources, including a Movement Disorder Specialist, who focuses on the treatment of PD.
- Share the benefits of a holistic care team (i.e.: How a speech therapist can help you as your PD progresses).

To learn more go to www.pdadvocates.com

If you don't have access to the internet to register, a family member or friend can help you register with your permission.

The Parkinson's Disease Advocate Program is not a replacement for a medical professional, and the Advocate will not provide medical advice.

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Message from Art Guyer: It is hard to believe another year has passed. And what a year it has been. The "Managing Parkinson's Disease" seminar we put on in April was a huge success with about 100 people attending. Working with staff from the Johns Hopkins Parkinson's and Movement Disorders Center and the Hospice of Washington County, our Board structured an almost flawless event that got rave reviews by those who attended.

Thanks to Dave DeHaven's efforts, we have continued our card games and added a monthly bowling afternoon where we get 15 - 18 members out to have a good time on the duck pin lanes. Our picnics have been wonderful and our caregivers' breakfasts have been useful. The trip to the Totem Pole Theater at Caledonia State Park in Pennsylvania has also been popular, as well as the group dinner afterward.

Your support group is still growing and getting more active all the time. We are now averaging 50 attendees a meeting and set an all-time record of 73 at a meeting at which Becky Dunlop spoke. We have had 11 speakers this past year, covering many aspects of PD. And next year's schedule looks just as good. Have a happy holiday and safe New Year. Let's keep moving.

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Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

Heads Up, Caregivers!

Caring in Parkinson's

Parkinson's Disease Foundation

The challenge for individuals with Parkinson's disease is to remain as independent as possible. For some people, this means doing everything themselves, even if it takes longer. For others, varying amounts of assistance are needed.

The need for assistance often fluctuates throughout the day and may depend on how well the medications are working at a specific time. In the "on" medication state, some people are fully functional and mobile, but in the "off" state, they may require assistance for daily activities such as dressing, eating and walking.

It is important for family members to recognize the variable and sometimes unpredictable nature of Parkinson's disease disability. By staying alert and offering help when it is needed, family members can find the right balance between protecting the person with Parkinson's and encouraging independence.

Parkinson's disease does not just affect the person living with it – it affects the entire family and an extended community of friends and loved ones.

If you are the care partner, child, parent, grandparent or loved one to a person with Parkinson's, you are familiar with the challenges that come with living with the disease. Your responsibilities may include helping a loved one with daily activities, managing medications and making financial decisions.

As a care partner it may be difficult to let others help or to take time for yourself. Remember that it is as important for you, as it is for the person with Parkinson's, to care for yourself and to begin understanding the disease. Taking care of yourself can benefit both you and your partner. Benefits include revitalized energy, renewed interest in creative endeavors, new subjects to talk about and the realization that you and your partner are not alone.

How can you get started?

- **Find a support group:** For many people, support groups play an important role in the emotional well-being. Some groups are targeted towards care partners. They can provide a comfortable environment for asking questions, sharing experiences and advice, and creating friendships. PDF keeps a listing of nationwide Parkinson's support groups. To find one in your area, please call or email PDF at (800) 457-6676 or info@pdf.org.
- **Take Time for Yourself:** For those who have family in the area, friends and family are often willing to help, but are unaware of your needs. With their help you can find time to yourself. Consider making a list of things that others can do that may help you, if even for two to three hours. It may be difficult to get used to asking for help or even hiring help. But remember that since caregiving is a role you are in and undoubtedly wish to do well, you will need to care for yourself in order to offer the most you can.

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Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

Questionnaire

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? _____

Two New Therapies for Parkinson's Disease Patients to get Excited About: Vaccines and Monoclonal Antibodies

In September 2012, an NPF blog featured a new therapy that at that time had entered into human testing. The Austrian company AFFIRiS A.G. launched a two-year long clinical trial of a vaccine designed to stop Parkinson's disease progression. This month they updated the article on the vaccine and another therapy (monoclonal antibodies) for the treatment of Parkinson's disease.

Parkinson's disease is a neurodegenerative condition associated with deposition of a brain protein known as alpha-synuclein. This protein clumps and spreads throughout the brain, and the spread of the protein parallels the progression of Parkinson's disease. Many experts believe much of the damage in Parkinson's disease traces to the brain's failure to process, and to clear these bad proteins.

The idea underpinning the Parkinson's disease vaccine is simple. Patients receive injections with the hope that these injections will stimulate an immune system response against alpha-synuclein, and that antibodies will attack these brain proteins; and ultimately clear them. Thirty-two human Parkinson's disease patients were part of a two year safety and tolerability study called the PD01A project. The study ultimately would be the first step in modifying disease progression in human Parkinson's disease patients.

The preliminary results of the study revealed the vaccine was safe and well-tolerated, though relatively few people were tested. Half of those in the study developed antibodies against alpha-synuclein, and for those patients the investigators believe that the appearance of antibodies was a positive sign. Why some patients did not develop antibodies remains unknown, and a follow-up study will address the use of booster vaccine shots.

Using a different approach, Prothena and Roche are developing monoclonal antibodies (i.e. antibodies that are specific and only bind to a single substance) that will directly target alpha-synuclein. What is the difference between monoclonal antibodies and a vaccine? The monoclonal antibodies are injected into the patient as a direct therapy, whereas the vaccine shot stimulates the immune system to produce antibodies against alpha-synuclein. Both are considered under the umbrella of "immunotherapies." Two dose-finding and human safety trials of the first Parkinson's monoclonal antibody PRX002 are underway.

It is important to keep in mind that not all experts believe that removal of these brain proteins will result in clinically meaningful changes and/or disease modification. Additionally, one highly publicized attempt to target amyloid in Alzheimer's patients led to serious safety concerns, and termination of a vaccine study known as AN1792 because several patients developed a meningoencephalitis.

What patients need to know is that both are still in the very early stages of testing, but that the idea of boosting immunity and using immunotherapy is novel and promising. Safety, tolerability, and clinical efficacy will need to be demonstrated before the vaccine and the monoclonal antibodies can move into the next phase of clinical testing. Our hope is that clearance of the Parkinson's associated brain proteins will translate into disease modification. A similar approach is also being tested in other diseases such as Alzheimer's disease, diabetes, and atherosclerosis. These are definitely potential Parkinson's disease therapies to get excited about.

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Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

Reminders of upcoming events as of Saturday, December 06, 2014

View our local Parkinson's Support Groups Calendar at: <https://www.localendar.com/public/HPSG>

- Tuesday, December 9, 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. Contact Cheryl Reames for more information at 540-662-4632 or cwreames@gmail.com.
- Friday, December 12, 2014: Berkeley County Parkinson's Support Group Annual Christmas Party at 5:30 PM. Contact Debi Corbin at 304-886-8594 for more information.
- Monday, December 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, December 16, 2014 (3rd Tuesday): Chambersburg PD Support Group Monthly Meeting at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Warren Leach at 717-264-2908 for information. Bailey Vernon from Johns Hopkins is the featured speaker.
- Wednesday, December 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 Silvius at 301-845-6514 or jsilvius@yahoo.com.

2015

- Thursday, January 8, 2015 (2nd Thursday): Monthly HSPG Meeting at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Speaker: Dr. Kelly Mills, neurologist from Johns Hopkins. Call Art at 240-625-2722 for information or directions.
- Friday, January 9, 2015 (1st 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.
- Tuesday, January 13, 2015 (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. Contact Cheryl Reames for more information at 540-662-4632 or cwreames@gmail.com.
- Thursday, January 15, 2015: 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, January 16, 2015: HPSG Cards at TBD at 1:00 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
- Monday, January 19, 2015 (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.
- Wednesday, January 21, 2015 (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 Silvius at 301-845-6514 or jsilvius@yahoo.com.
- Wednesday, January 28, 2015 (4th 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.

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2015

- Thursday, February 5, 2015 (1st 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 (1st 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 simckinney@atlanticbb.net. Kierstin Stevenson a physical therapist will be the speaker.
 - Tuesday, February 10, 2015 (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. Contact Cheryl Reames for more information at 540-662-4632 or cwreames@gmail.com.
 - Monday, February 16, 2015 (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.
 - Wednesday, February 18, 2015 (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 Silvius at 301-845-6514 or jsilvius@yahoo.com.
 - Thursday, February 19, 2015: 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, 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 (4th 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 (1st 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 (1st 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 simckinney@atlanticbb.net. Video: "You are Not Alone".
 - Tuesday, March 10, 2015 (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. Contact Cheryl Reames for more information at 540-662-4632 or cwreames@gmail.com.
 - Monday, March 16, 2015 (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.
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