Hagerstown, MD and the Four-State Area

# Monthly Newsletter

#### May 2015

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

Volume 5, Issue 5

Visit us on Facebook

#### **May Meeting**

#### **Local Support Group Contacts**

#### This Month's Meeting

We had 59 attendees at our April 2nd meeting, including 6 new attendees.

Our speaker for April was Registered Nurse, Arita McCoy, a coordinating nurse from the Johns Hopkins Parkinson's Disease and Movement Disorders Center. She made an excellent presentation briefly explaining Parkinson's Disease, potential causes, symptoms, and treatment. She also discussed new medications and medication delivery systems. Arita answered many questions from the group and continued her discussion with members during lunch. Everyone was very complimentary about her presentation and delivery.

Linda Embly 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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#### MARK YOUR CALENDARS

Join us for our next **Parkinson Support Group Meeting** at the

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, May 7, 2015, 11:45 AM

In May our speaker will be Lori Markland Assistive Technology Specialist, Maryland Office of Disabilities

#### **Newsletter Highlights**

Tips for Making Life Easier (Page 3) Breath Test for Parkinsons (Page 4) Other Support Group Activities (Page 5) Heads Up, Caregivers! (Page 6) Detailed Event Listing (Pages 7 & 8)

#### Survey Follow-up:

Now that we have some very good feedback and suggestions as a result of our survey, we need some volunteers to get together to discuss ways in proceed. Those interested in meeting to discuss these items should contact me ASAP. I will arrange a time and place to have a meeting sometime this month.

If you are happy with our support group, now is the time to step up and contribute. If you are **not happy**, this is your chance to make a difference.

#### **Future Meetings**

May 7, Lori Markland, Assistive Technology June 4, Stephanie Mahan, LSVT/BIG July 9, Breakout Sessions June 19. Picnic at Snook Memorial Park August 6, Becky Dunlop, JHU Sept. 3, Richard Lewellen, Music Therapist Sept. 18, Picnic at Snook Memorial Park October 1, Dr. Joseph Savitt, Neurologist Nov. 5, Amanda Distefano, WCHD, Falls December 3. Breakout Sessions

Berkeley County Parkinson's Support Group Debi Corbin, Facilitator, 304-886-8594 danicasgma@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 simckinney@atlanticbb.net

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

Friends in Frederick Parkinson's Support Group Contact Janet Silvious, 301-831-5609, janet@fifpdsg.org or John Kraft, 301-845-6514, john@fifpdsg.org. 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

Central PA PD Support Group - West Shore (Mechanicsburg, PA) Dan Yother, 304-676-2053, oldred714@verizon.net

Gettysburg Parkinson's Disease Support Group Paula Chaplin, 717-337-4407, pchaplin@wellspan.org

#### **Attend a Support Group Meeting**



Parkinson's Events Calendar On-Line.

The Hagerstown Parkinson's Support Group

Group Facilitator: **Art Guyer** 22215 Troy Lane Hagerstown, MD 21742 240-625-2722 4Parkinsons@gmail.com

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.

Hagerstown, MD and the Four-State Area

# **Monthly Newsletter**

# May 2015

#### Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month. In March, **Dave DeHaven**, **Mike Saterbak**, **Ecile Shaw**, **Peg Hayzlett**, **Carol Gaines and Art Guyer** enjoyed the Caregivers' Breakfast at the new location.

This month caregivers will meet for breakfast on April 20th, at the <u>Hagerstown Family Diner</u> at 8:30 AM. This restaurant is located at 431 Dual Highway (Rt 40 South) near the Best Western Grand Venice Hotel. Call Art if you need more information or directions.

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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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.





## Dancing for PD

Hugh McSweyn from our Support Group has made arrangements to brief anyone interested in "Dancing for Parkinson's" at 10:00 AM on Thursday, April 9, 2015. This meeting will take place at the Concordia Lutheran Church, 17906 Garden Lane, Hagerstown, MD. Concordia is about 5 minutes from where we hold our monthly meeting. For the initial meeting he will hold an open discussion period, review as much of the DVD as anyone wants, then close with a short comment period.

You can contact Hugh at 717-401-0692 or hugh.mcsweyn@comcast.net.

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## 2015 Picnics

Our picnics this year are scheduled for June 19 and September 18 at the Martin L. Snook Memorial Park, Pavilion #4 in Hagerstown, MD.

We will get the fried chicken, drinks, utensils, and paper products; you bring a covered dish or dessert to share with the group. The cost of the pavilion and chicken will be prorated to those attending; historically this has been about \$4 a person.

There will be free bingo; everyone should bring one or more wrapped, inexpensive "prizes" for the winners. There will be a group photo, guessing games and other fun opportunities, including some special entertainment at the September picnic.

Contact Art for information or to register.

#### **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. Our next game is going to be on April 21<sup>st</sup> at 1:00 PM at the home of **Harry Davis**.

## **PD Group Bowling**

To get better lane assignments, we have changed our bowling days to the third Friday of every month. On Friday, April 17th we will meet 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 April

Happy Birthday to our members who have April birthdays: Bob and Jean Teufel, Lu Mattern, Shirley Smith, Nancy Glenn, Carl Lowery, Gracie Churchman, Peg Hayzlett, Betty Martin, Julia Springer, Bill Flour and new member Harold Jones.

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 is our Sunshine Committee of One and is responsible for sending out cards as appropriate.

Call Barb at 301-797-7845 or contact Art if you know someone in need.

Hagerstown, MD and the Four-State Area

# **Monthly Newsletter**

May 2015

## Tips for Making Life Easier Based on the Book by Shelley Peterman Schwarz (2002)

Look for ways to reduce your stress level and put yourself and your needs first. This is not selfish or self-centered. You must take care of yourself first. You are the authority regarding your own body. Rest when you are tired. Be protective about how you spend your time and energy. Parkinson's disease uses a great deal of one's physical energy. Coping and adapting take a great deal of emotional and mental energy. Do the things that are important to you and your family. Give yourself permission to say "NO," and don't feel guilty. When you are feeling better, you can say "YES."



Make the best of good days with your family and friends doing something you enjoy.

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#### This and That .... Thoughts on my Mind by Art Guyer

Wow, it has been a long time between meetings due to the inclement weather closing last month. April is "Parkinson's Disease Awareness Month" and as a result it is a busy time of the year for those who are associated with the disease. It even looks like May will be busy too. Then the Totem Pole productions begin. Take a look at the schedule starting on page 7 of this newsletter for details on the upcoming events.

There are somethings I want to highlight because they are especially important:

- On April 24<sup>th</sup> there is a PD Caregiver Training Program put on by Johns Hopkins. See page 6 for details. A couple of us are signed up for this program and I have room for one more in my truck if you would like to go.
- How about going to a Frederick Keys Baseball Game? On April 25<sup>th</sup> the Frederick Support Group is hosting a PD group day at the park. See page 5 for details. If you want to go, you must register immediately. Doris and I are planning to go and could take two others down with us.
- On Friday, May 8, 2015, an educational event -- Within Our Reach University of Maryland Annual Parkinson's Disease Symposium -- is being held at the BWI Marriott in Baltimore, MD from 8AM 2:45 PM. Contact Michelle Cines at 410-328-0157 or <a href="mailto:mcines@som.umaryland.edu">mcines@som.umaryland.edu</a> for more details. Doris and I are going to this; we go down the day before and stay at the hotel two nights so we don't have to travel early and the room is available for respite if necessary during the event. We have room in the truck for another couple if anyone else would like to travel with us.
- Washington County CARES presents its annual Senior & Caregiver Expo at Hager Hall Conference Center, 901 Dual Highway on Thursday, May 14, 2015, beginning at noon. Call 301-791-3087 for more information. We will be having an information table at this event.
- As I mentioned earlier, Totem Pole productions are beginning soon and some of the shows are beginning to sell out of
  the better seats. Contact me for discounted tickets if you are interested in going to any of the shows (excluding
  "Lovesick Blues). The DeHaven's and Doris and I are subscribers and will be going to all of the productions.

One of the aspects of our support group that I try to emphasize is the importance of continuing to be interactive with others in a social environment. We have such a good, loyal group of people it makes it easy to spend time with each other. I encourage you all to take advantage of the opportunities we try to provide, including those sponsored by other support groups and the centers of excellence. I have flyers for these events so feel free to contact me for more information. Hope to see some new faces at our events, in addition to all of the regulars.

Hagerstown, MD and the Four-State Area

# **Monthly Newsletter**

May 2015

# Breath Test Shows Promise for Distinguishing Parkinsonian Disorders Parkinson's Disease Foundation (March ,4 2015)

A relatively simple breath test may one day be able to help diagnose Parkinson's disease (PD) and distinguish the disease from other disorders with similar symptoms, according to a study published in the February issue of *Parkinsonism and Related Disorders*.

Doctors diagnose PD mainly by interpreting a person's movement symptoms, which can include tremor, stiffness, slowness of movement and balance difficulties. However, it can be difficult to distinguish between PD and other causes of parkinsonism such as Parkinson's plus syndromes. These diseases, which include Lewy body dementia, multiple system atrophy and progressive supranuclear palsy, have symptoms similar to those of PD.

For the new study, researchers led by Hossam Haick, Ph.D., and Samih Badarny, M.D., at Technion - Israel Institute of Technology, in Haifa, analyzed molecules in the breath of 97 people – 44 people with PD, 16 people with a variety of Parkinson's plus syndromes and 37 healthy individuals. Two breath samples from each participant were passed over an "electronic nose," a sensor called a nanoarray. The sensor generates electric signals, which in turn identify molecules called volatile organic compounds released in a person's breath. The presence and quantity of certain molecules create a breath "signature." The researchers followed participants for three years after the breath tests, and confirmed that diagnoses had not changed.

#### Results

- About 88 percent of the time, the breath test correctly distinguished between people with PD and people with other causes of Parkinsonism, i.e., Parkinson's plus diseases.
- Breath analysis correctly distinguished between people with Parkinson's plus syndromes and healthy individuals about 85 percent of the time.

The new study presents interesting preliminary results for a simple, noninvasive way to distinguish PD from syndromes with similar symptoms. Studies with larger numbers of participants are needed before this technique can be developed further. Potential weaknesses of the study are first, that the gold-standard method for PD diagnosis, autopsy, was not an available option here (i.e., some study participants may have been misdiagnosed) and second, that breath samples were not evaluated in a blinded fashion.

A simple way to definitively diagnose PD is urgently needed. Currently, there are no blood tests or other biomarkers to do this. Certain brain scans may help distinguish different syndromes with Parkinsonian symptoms, but these tests require equipment and expertise beyond what is available in a typical neurologist's office.

Even if a breath test for PD does not come to fruition, the researchers did identify several volatile organic compounds that were at a higher concentration than in people with PD. Understanding how changes in a person's metabolism lead to changes in the breath signature might also provide another avenue for creating a laboratory test to identify and differentiate PD from other conditions.

Beyond PD, nanoarray breath analysis is being investigated for diagnosing certain cancers, multiple sclerosis and diabetes. In addition, the authors of this study, in an earlier small study, found that people with PD had different breath signatures than people with Alzheimer's disease.

Hagerstown, MD and the Four-State Area

# Monthly Newsletter

May 2015



## Friends in Frederick Parkinson's Disease Support Group

www.fifpdsg.org

The "Friends In Frederick" Parkinson's Disease Support Group is going to a Frederick Keys baseball game for Parkinson Awareness Month and you are invited to attend the game with them.

This is a \$2 savings per ticket if purchased by the group in advance.

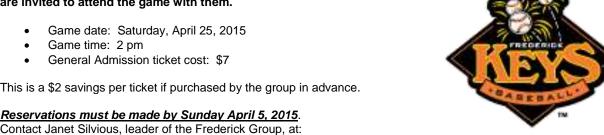
#### Reservations must be made by Sunday April 5, 2015.

Phone: 301-831-5609 Email: jsilvious@yahoo.com

The Stadium is handicap friendly, including wheelchairs.

If you want to tour the seating in the stadium, you can see it during the week.

The Group plans to do a press release afterwards that talks about the event and contains information about Parkinson's Disease and local support groups.



**Danc'n for Parkinson's:** The <u>Cumberland PD</u> Support Group is holding a special Fundraiser-Dance at the Cresaptown Eagles on Saturday, May 23 from 7:00 to 9:00PM. It will be open to the public and there will be no admission charge. Music will be provided by Summer Wind, Shirley and Ken McKinney's own Band. Come and enjoy an evening of fun with friends. There will be a "Chinese Auction" and several fun ways to donate a couple of bucks.

The Eagle's Ladies Auxiliary is providing the facility fee. Call 301-729-1427 for more information.

## **Winchester Parkinson's Support Group**

The Winchester group is currently promoting a number of entertaining and beneficial activities for persons with Parkinson's Disease:

- Vocal Choir
- Dance for Parkinson's
- Billiards
- Ping Pong

Cheryl Reames, Facilitator, 540-662-4632 or winchesterparkinson@gmail.com

Hagerstown, MD and the Four-State Area

# **Monthly Newsletter**

May 2015

#### **Heads Up, Caregivers!**



# Parkinson's Disease Caregiver Training

When: Friday April 24, 2015 from 10:30 AM to 3:30 PM EDT

Where: Howard County Library, Miller Branch, 9421 Frederick Road, Ellicott City, MD

Contact: Bailey Vernon

Johns Hopkins Parkinson's Disease and Movement Disorders Center

410-616-2811

bvernon1@jhmi.edu

The Johns Hopkins Parkinson's Disease Movement Disorders Center presents a program of "Caregiver Training for Parkinson's Disease and Related Movement Disorders." This program is a special opportunity for those who care for someone with Parkinson's disease or a related movement disorder to learn from expert presenters and connect with other care partners. All family members and friends are invited to attend. Registration is required and the fee is \$15 which includes lunch.

#### Agenda

- 10:30 Registration
- 10:45 Caring for the Caregiver, Kathy Schey, MAgS
- 11:30 The Caregiver Experience, Panel facilitated by Becky Dunlop, RN, MS
- 12:30 Lunch
- 1:30 Navigating Health Care Needs in Parkinson's Disease, Arita McCoy, RN, BS
- 2:15 Practical Pointers for Caregivers, Janice Sallitt, PT, DPT, NCS
- 2:55 Comfort Care Advanced Planning, Debbie Shpritz, PhD, RN
- 3:30 Program Concludes

More information and registration can be found at: <a href="http://tinyurl.com/PDCaregiver2015">http://tinyurl.com/PDCaregiver2015</a>

Hagerstown, MD and the Four-State Area

# **Monthly Newsletter**

May 2015

#### **REGULAR EVENTS:**

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 <sup>st</sup> Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 <sup>st</sup> Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Shirley McKinney, 301-729-1427 sjmckinney@atlanticbb.net
Winchester PD Support Group Monthly Meeting	2 <sup>nd</sup> Tuesday @ 11:00 AM Winchester Church of God, Winchester, VA	Cheryl Reames, 540-662-4632 cwreames@gmail.com
Central PA PD Support Group Meeting	2 <sup>nd</sup> Wednesday @ 1:30 PM Health South Rehab Hospital, Mechanicsburg, PA	Dan Yother, 304-676-2053 oldred714@verizon.net
Hagerstown Parkinson's Support Group – Caregivers' Breakfast	3 <sup>rd</sup> Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Chambersburg PD Support Group Meeting	3 <sup>rd</sup> Tuesday @ 2:00 PM Menno Haven, Chambersburg, PA	Warren Leach, 717-264-2908 SkipL815@aol.com
Frederick PD Support Group Monthly Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
Hagerstown Parkinson's Support Group Cards	3 <sup>rd</sup> Thursday @1:00 PM Location Varies	Dave DeHaven, 301-582-2815 hagdehaven@aol.com
Hagerstown Parkinson's Support Group Bowling	3 <sup>rd</sup> Friday @ 1:00 PM Southside Bowls, Hagerstown, MD	Dave DeHaven, 301-582-2815 hagdehaven@aol.com
Frederick County Parkinson's Early Onset or Newly Diagnosed Community Support Group	3 <sup>rd</sup> Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 dfbergstrom@comcast.net
Berkeley County Parkinson's Support Group	4 <sup>th</sup> Wednesday @ 6:30 PM Otterbein United Methodist Church, Martinsburg, WV	Debi Corbin, 304-886-8594 danicasgma@aol.com

#### **OTHER EVENTS:**

- Thursday, April 9, 2015: Dancing for Parkinson's -- Hugh McSweyn from our Support Group will discuss and demo a DVD on this topic at the Concordia Lutheran Church, 17906 Garden Lane, Hagerstown, MD. You can contact Hugh at 717-401-0692 or hugh.mcsweyn@comcast.net for registration or information.
- Saturday April 11, 2015: Health & Wellness Expo at the Valley Mall from 10:00 AM to 6:00 PM. Come find our table.
- <u>Saturday April 11, 2015: Managing PD Symposium: 2015 Update in Chevy Chase, MD</u> at 9:15 AM 12:30 PM. Call 202-364-7602 for information and registration.
- <u>Friday, April 24, 2015</u>: <u>PD Caregiver Training</u> at the Howard County Library, Miller Branch, 9421 Frederick Road, Ellicott City, MD at 10:30 AM 3:30 PM. Contact Bailey Vernon, 410-616-2811 or <u>bvernon1@jhmi.edu</u>.

Hagerstown, MD and the Four-State Area

# **Monthly Newsletter**

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May 2015

- <u>Saturday, April 25, 2015: Friends in Frederick PD Support Group goes to a Keys Baseball Game</u>. Game time is 2:00 PM; general admission is \$7 when purchased in advance by April 5<sup>th</sup>. Contact Janet Silvious at 301-831-5609 or jsilvious@yahoo.com. You are invited!
- <u>Tuesday, April 28<sup>th</sup>, 2015</u>: Stepping On Fall Prevention Program. Seven sessions at the Washington County Senior Center.
   Call 240-313-3357 for information or to register.
- Monday, May 4, 2015: PD 101 in Westminster, MD. RSVP by April 23; \$15 fee includes lunch. Information and Registration at 410-871-7000.
- <u>Friday, May 8, 2015 Within Our Reach University of Maryland Annual Parkinson's Disease Symposium</u>: At the BWI Marriott in Baltimore, MD from 8AM 2:45 PM. Contact Michelle Cines at 410-328-0157 or <u>mcines@som.umaryland.edu</u> for more details.
- Thursday, May 14, 2015: Senior & Caregiver Expo and Dinner at Hager Hall Conference Center, 901 Dual Highway from Noon until evening. Call 301-791-3087 for more information.
- Thursday, May 21, 2015: Networking Meeting for Parkinson's Support Group Leaders at the Towson Unitarian Universalist Church, Lutherville, MD from 10:00 AM 2:00 PM. Contact Bailey Vernon at 410-616-2811.
- <u>Saturday, May 23, 2015, Four-State Alliance for Parkinson's Support Leadership Meeting</u>: Alliance leaders will meet at the Western Sizzlin' Restaurant in Hagerstown from 11:00 AM to 3:00 PM.
- <u>Saturday, May 23, 2015, Dancin' for Parkinson's</u>: The Cumberland PD Support Group is holding a Dance/Auction as a fundraiser at the Cresaptown Eagles Club from 7:00 to 9:00 PM. Free Admission. Contact Shirley McKinney for more information and directions at 301-729-1427 or <a href="mailto:simple:simp
- <u>Wednesday</u>, <u>June 10</u>, <u>2015</u>: <u>Totem Pole The Nerd</u>. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.
- <u>Friday, June 19, 2015: HPSG Summer Picnic</u>, from Noon to 3:00 PM, at the Martin L. Snook Memorial Park, Pavilion #4, Hagerstown, MD. Call Art at 240-625-2722 or email <u>4Parkinsons@gmail.com</u> for information or directions and to register.
- <u>Friday, June 26, 2015: Johns Hopkins Newly Diagnosed Forum</u> at Green Spring Station, Lutherville, MD from 9:00 AM to Noon. Contact Bailey Vernon at 410-616-2811.
- Wednesday, July 1, 2015: Totem Pole Shenandoah. Show time 2:00 PM. Call Art at 240-625-2722 for information or
- Wednesday, July 22, 2015: Totem Pole Lincoln. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.

- <u>Held to the first of the first</u>
  - Wednesday, August 19, 2015: Totem Pole Lovesick Blues. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.
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