

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

June 2015

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

Volume 5, Issue 6

[Visit us on Facebook](#)

This Month's Meeting

We had **51 attendees** at our **May 7th** meeting, including **9 new attendees**, a number of which were from the Berkeley County Parkinson's Support Group. We also had two guests: **Amanda Distefano**, a communication and education specialist from the Washington County Health Department who was invited to hear our speaker, and **Nadine Yoritomo**, a Senior Research Nurse Coordinator at Hopkins who wanted to address our group concerning the need for healthy controls in their MARK-PD study.

Our featured speaker for May was Denise Schuler, the Assistive Technology Specialist from the Maryland Technology Assistance Program, under the Maryland Department of Disabilities located in Baltimore, MD. Her presentation was excellent and she demonstrated a number of devices that can help the disabled in their activities of daily living. If you have any questions about this subject, you can reach Denise at 800-832-4827 or by email at dschuler@mdtap.org. She can only assist Maryland residents, but she provided the following URL from which you can get in contact with similar resources in any state:

www.ataporg.org/states_listing.html.

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Jay Stouffer won the \$10 gift certificate to the Western Sizzlin' Restaurant donated by Paul Romsburg and his family.

Thanks go to **Ecile Shaw** for asking the blessing.

June Meeting

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the
Western Sizzlin Steakhouse
17567 York Road, Hagerstown, MD

Thursday, June 4, 2015, 11:45 AM

In June our speaker will be
Stephanie Mahan
LSVT/BIG
Presentation

Newsletter Highlights

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Future Meetings

June 4, Stephanie Mahan, LSVT/BIG
June 19, Picnic at Snook Memorial Park
July 9, Breakout Sessions
August 6, Becky Dunlop, RN, 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
2016
Jan. 7, David Kukor, Accessible Home Care
Feb. 4, Cathy Hanson, Alzheimer's Association
Mar. 3, Michelle Cines, RN, Univ. of MD Med. Ctr

Local Support Group Contacts

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

Winchester Area Parkinson's Support Group
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
skip1815@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@wellspring.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.

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Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3rd Monday of every month. In April, **Dave DeHaven, Mike Saterbak, Ecile Shaw, Peg Hayzlett, Carol Gaines, Barb Harrell, Art Guyer and Carolyn Shuman** enjoyed the Caregivers' Breakfast. We also had a special guest, **Mr. Robert Lindsay** from Gettysburg who is in the process of formulating a presentation about his Parkinson's Disease journey.

This month caregivers will meet for breakfast on **May 18th**, at the **Hagerstown Family Diner** at 8:30 AM. This restaurant is located at 431 Dual Highway near the Best Western Grand Venice Hotel. Call Art if you need more information or directions.

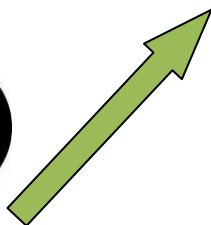
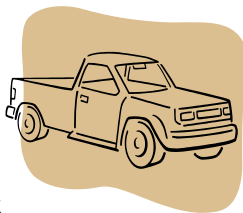
You are encouraged to participate if possible. It gives caregivers the opportunity to seek advice in a safe environment and it allows feedback for future meetings and activities. If you need transportation, let us know and we will take care of it.

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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.



Dancing for PD

Hugh McSweyn from our Support Group is interested in conducting a Dancing for PD exercise program using a DVD he has purchased.

If you are interested, you can contact Hugh at 717-401-0692 or by email at 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.

PD Group Bowling

Bowling has been put on hold due to other activities and the limited openings available at the bowling alley.

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

Birthdays in May

Happy Birthday to our members who have April birthdays: **Bob Dieterich, Julia Springer, Melody Garry, Leona Sites, Austin Gladhill, Die Schumacher, Cliff Smith, Kate Jenkins, Leona Watson, and Art Guyer**.

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.



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Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

Try not to be self-conscious about the visible symptoms of your Parkinson's disease. Work around the problems. If you are self-conscious about the way you walk, consider using a wheelchair. If hand tremors make it difficult to eat with utensils and you are embarrassed to eat out in a restaurant, order foods you can eat with your hands and ask the waitress to put each item on a separate plate or bowl; that way your tremors are less likely to knock food off the plate. Don't let your visible symptoms of PD diminish the enjoyment you get from spending time with your family and friends.

And remember your support group friends all have similar symptoms so when you spend time with them, all of the symptoms "disappear." If you have not already done so, attend a meeting, card game, bowling event, picnic, etc. Get out and have some fun.



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This and That Thoughts on my Mind by Art Guyer (with some help from the Michigan Parkinson Foundation)

Two people in a doctor's waiting room happen to strike up a conversation. They are soon sharing information and asking each other about medication and how to handle difficulties presented by Parkinson's Disease. An informal support group has begun.

Who knows more about PD than the people who live with it and their partners who help with the struggle? A support group does exactly what that doctor's waiting room did - it brings together people with a common bond. Unlike the doctor's office, a support group validates people's concerns by also looking after their emotional needs. How many people, after their first visit to a support group, were heard to say, "And I thought I was the only one with this problem."

A support group is a tremendous pool of knowledge and experience. Members are encouraged to share how:

- To cope with the day-to-day challenges,
- To get the most from their visit to the doctor,
- To ask intelligently about medication and therapy,
- To instruct hospital staff in event of an admission,
- To define what's important in life and what can be left behind
- To tell family and friends about PD (they notice it before you realize they do),
- To empathize with other people in the same situation,
- To maintain a good attitude and even laugh at adversity

Support groups become a large family of understanding, sympathetic, and encouraging patients, caregivers, and concerned friends. Each group has a personality, defined by its members. Some people may attend more than one support group, because their needs are greater than can be satisfied once a month.

Support groups are informal - all are welcome. Often, there will be a speaker - doctor, pharmacist, therapist, counselor, humorist, lawyer, or other professional. Some meetings will be a free-spirited discussion among its members about topics of great interest. Or the facilitator may have arranged something special - dinner at a restaurant or a trip to the park. Don't be afraid to speak to the facilitator about what interests you.

There's a saying that you get as much from an activity as you put into it. Nobody will force you to speak during a group discussion, but you will benefit more if you share your feelings and thoughts. The facilitator always appreciates a helping hand, even if it is an occasional few minutes to help greet new members or to organize one meeting.

Remember - the support group is for your benefit. Use it wisely and often. Pitch in your two cents!

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Apathy and Parkinson's Disease

By: Heather Simpson and Michelle Foley, OTS

One of the biggest non-motor complaints for Parkinson's patients is a decline in motivation to participate in daily activities. If it is taking every effort to get off your couch or out of your bed to engage in desired activities, you may be experiencing a very common symptom of Parkinson's disease -- apathy. Apathy affects many patients with Parkinson's disease regardless of disease progression. It is manifested as a reduced lack of interest and participation in purposeful behaviors, difficulty with initiating, sustaining and completing tasks, and lack of concern for yourself and those around you. Family members and friends may be thinking you are just being "lazy" or "uninterested", but realize that apathy is caused by both physiological changes resulting from changes in the brain, including depletion of dopamine, and external factors of adjusting to a life with Parkinson's.

If you are experiencing symptoms of apathy it is important to talk to your health care provider about medical management of your symptoms. There are some useful tips to help increase your participation in needed and desired activities:

- Create or have assistance creating a daily schedule of activities, with set times to get things done. Make every effort to start and complete each task. Write these down on a daily planner or calendar and cross things off as you accomplish them. Include both activities that you enjoy and that simply just need to get done (i.e. mowing the lawn, housework). Make the plan realistic and not overwhelming.
- Create small weekly goals for leisure activities.
- Elicit the help of others to engage in an activity, not only will assistance of others help you accomplish the activity, but social interaction is motivation in itself and makes the activity more "fun".
- EXERCISE: Daily exercise not only can slow down the progression of Parkinson's disease, but also releases chemicals in the brain that elevates mood and increases motivation.
- SLEEP: Try to get a good night sleep every night. Sleep affects motivation for everyone, not just those with Parkinson's disease. Medication management may be necessary to minimize symptoms affecting sleep, but also consider establishing a nighttime routine (lower the lights, engage in relaxing activities such as reading, yoga, warm bath, soothing music) and avoid stressors such as the nightly news, emails and certain foods including caffeine and alcohol before bed-time. Ensure your environment is set up for restful sleep including a comfortable mattress, dark room, appropriate temperature and is free of distractions.
- Try to stay relaxed, consider deep breathing strategies, attending yoga or Tai Chi classes.
- Get out of the house: attend Parkinson's disease support group meetings, religious outings, dinner with friends...Being around others and engaging in interesting conversations and experiences can boost mood and enhance motivation. Try the Hagerstown Parkinson's Support Group bowling, cards, picnics, summer theater, etc. to get socially involved.



Remember that apathy and your lack of motivation is not your fault, but rather is related to the chemical changes in the brain. There may be medications available to assist with your symptoms and the above tips can help increase your participation in needed and desired activities.

Follow up with your physician, psychiatrists, psychologists or rehab therapists for further treatment of apathy if necessary.

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Other Support Group Activities:

"Friends" in Frederick PD Support Group

had a successful but chilly afternoon at Key's Stadium on April 25th for their Parkinson's Awareness Event. Connie and John Hipp and Connie's daughter, Faith Mattia, went to the game. That's Connie on the left.



The Early On-Set, Newly-Diagnosed PD Support Group in Frederick:

This new group will hold its next meeting on May 16 at the main library in Frederick in the community room and will start at 2:30 PM. Their guest speaker will be Dr. Stephen Grill from the Maryland Parkinson's and Movement Disorders Center in Elkridge. He will be giving a talk entitled "Thriving with Parkinson's".

Contact Deb Bergstrom at 301-712-5381 if you want to attend and need more information or directions.

Danc'n for Parkinson's:

The Cumberland PD 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

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

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Heads Up, Caregivers!

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. Free Bingo is between 1:00 and 2:00 PM. Call 301-791-3087 for more information. We will be having an information table at this event.

10 Tips for Family Caregivers

1. Seek Support from other caregivers. You are not alone. Look for caregiver support groups or subgroups such as our Caregivers' Breakfast.
2. Take care of your own health so you can be strong enough to take care of your loved one.
3. Accept offers of help and suggest specific things people can do to help you.
4. Learn how to communicate effectively with doctors.
5. Caregiving is hard work so take respite breaks often.
6. Watch out for signs of depression and don't delay in getting professional help when you need it.
7. Be open to new technologies that can help you care for your loved one.
8. Organized medical information so it's up to date and easy to find.
9. Make sure legal documents are in order.
10. Give yourself credit for doing the best you can in one of the toughest jobs there is!



SENIORS TEXTING CODE:

ATD: At The Doctors
BFF: Best Friend Fell,
BTW: Bring the Wheelchair,
BYOT: Bring Your Own Teeth,
FWIW: Forgot Where I Was,
GGPBL: Gotta Go Pacemaker Battery Low,
GHA: Got Heartburn Again,
IMHO: Is My Hearing-Aid On,
LMDO: Laughing My Dentures Out,
OMMR: On My Massage Recliner,
OMSG: Oh My! Sorry, Gas,
ROFLACGU: Rolling On Floor Laughing And
Can't Get Up
TTYL: Talk To You Louder.



New Member Julia Springer to Donate Part of Art Work Proceeds to MJFF. The artwork of Julia Springer, of Shepherdstown, WV, will be on display at the Shepherdstown Presbyterian Church from May 10 until June 7, 2015. Julia will be exhibiting works featuring Shepherdstown, and will be available to talk about her work and answer questions at an Artist's Reception at noon on Sunday, May 24. This is to benefit The Michael J. Fox Foundation for Parkinson's Research (MJFF); 33% of the purchase price of any pieces sold or ordered directly from the artist during the event will be donated to the MJFF.

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Reminders of upcoming events as of Monday, May 11, 2015

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

REGULAR EVENTS:

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1st Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1st Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Shirley McKinney, 301-729-1427 sjmckinney@atlanticbb.net
Winchester PD Support Group Monthly Meeting	2nd Tuesday @ 11:00 AM Winchester Church of God, Winchester, VA	Cheryl Reames, 540-662-4632 cwreames@gmail.com
Central PA PD Support Group Meeting	2nd 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	3rd Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Chambersburg PD Support Group Meeting	3rd Tuesday @ 2:00 PM Menno Haven, Chambersburg, PA	Warren Leach, 717-264-2908 SkipL815@aol.com
Frederick PD Support Group Monthly Meeting	3rd Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3rd Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
Hagerstown Parkinson's Support Group -- Cards	3rd Thursday @ 1:00 PM Location Varies	Dave DeHaven, 301-582-2815 hagdehaven@aol.com
Hagerstown Coffee Talk Networking Leaders	3rd Thursday @ 8:15 AM Location Varies	K.C. Ryerson, 301-257-7745 kryerson@nbseniorliving.com
Hagerstown Parkinson's Support Group -- Bowling	3rd Friday @ 1:00 PM (Check First) Southside Bowls, Hagerstown, MD	Dave DeHaven, 301-582-2815 hagdehaven@aol.com
Frederick County Parkinson's Early Onset or Newly Diagnosed Community Support Group	3rd Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 dfbergstrom@comcast.net
Berkeley County Parkinson's Support Group	4th Wednesday @ 6:30 PM Otterbein United Methodist Church, Martinsburg, WV	Debi Corbin, 304-886-8594 danicasgma@aol.com
Memory Café	4th Thursday @ Noon Always Ron's Restaurant, Hagerstown, MD	David Kukor, 301-639-3166 dkukor@ahcglobal.com

OTHER EVENTS:

- Thursday, May 14, 2015: Senior & Caregiver Expo and Dinner at Hager Hall Conference Center, 901 Dual Highway from Noon until evening. Bingo from 1 to 2; Exhibits all afternoon; Dinner at 5:30; 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.

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- Saturday, May 23, 2015, Dancin' for Parkinson's: 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 sjmckinney@atlanticbb.net.

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- Wednesday, June 10, 2015: Totem Pole – The Nerd. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.

- Friday, June 19, 2015: HPSG Summer Picnic, 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 4Parkinsons@gmail.com for information or directions and to register.

- Friday, June 26, 2015: Johns Hopkins Newly Diagnosed Forum at Green Spring Station, Lutherville, MD from 9:00 AM to Noon. Contact Bailey Vernon at 410-616-2811.

- Saturday, June 27, 2015, Four-State Alliance for Parkinson's Support Leadership Meeting: Alliance leaders will meet at the Western Sizzlin' Restaurant in Hagerstown from 11:00 AM to 3:00 PM.

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- Wednesday, July 1, 2015: Totem Pole – Shenandoah. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.

- Wednesday, July 22, 2015: Totem Pole – Lincoln. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.

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- Wednesday, August 12, 2015: Totem Pole – Grease. Show time 2:00 PM. Call Art at 240-625-2722 for information or directions.

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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- Friday, September 18, 2015: HPSG Summer Picnic, 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 4Parkinsons@gmail.com for information or directions and to register.

- Saturday, September 26, 2015, Four-State Alliance for Parkinson's Support Leadership Meeting: Alliance leaders will meet at the Western Sizzlin' Restaurant in Hagerstown from 11:00 AM to 3:00 PM.

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- Friday, October 23, 2015: Johns Hopkins Newly Diagnosed Forum at Green Spring Station, Lutherville, MD from 9:00 AM to Noon. Contact Bailey Vernon at 410-616-2811.

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- Wednesday, November 4, 2015: Johns Hopkins Deep Brain Stimulation Information Sessions at Green Spring Station, Lutherville, MD from 6:00 PM to 8:00 PM. Contact Bailey Vernon at 410-616-2811.

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