

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

September 2015

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

Volume 5, Issue 9

[Visit us on Facebook](#)

This Month's Meeting

We had another **record breaking crowd of 73 at our meeting** on **August 6th**, including 16 new attendees and special guests. This is the 2nd year in a row that Becky Dunlop, the Associate Director of the Johns Hopkins Parkinson's Disease and Movement Disorders Center, has packed the room. She disappointed no one and did a great job answering members' questions in great detail.

Becky discussed the two major drug advancements approved by the FDA at the beginning of this year and explained how and why they were effective. She answered questions on sleep issues; the benefits of movement disorder specialists and how they related to other doctors; deep brain stimulation; and many others on symptoms of and treatments for Parkinson's Disease. She continued discussing issues with members throughout lunch.

In addition, two representations from **NMS Wellness** attended the meeting to get familiar with our support group. We will have more information on a proposal they have made at a later date.

Dan Yother, the Co-Facilitator for the Central PA Parkinson's Disease Support Group - West Shore (Mechanicsburg, PA) joined us for this meeting too. Also, **Bob Lindsay** and several others from the Gettysburg area joined us to hear and meet Becky Dunlop.

Thanks to **Mike Saterbak** for saying our prayer before lunch.

September Meeting

MARK YOUR CALENDARS

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

Thursday, September 3, 2015, 11:45 AM

Our Speaker for September is
Mr. Richard Lewellen
Music Therapist

Newsletter Highlights

Tips for Making Life Easier ([Page 3](#))
Heads Up, Caregivers! ([Page 4](#))
Fall Picnic Flyer ([Page 5](#))
Diabetes Drug Trial Results ([Page 6](#))
Detailed Event Listing ([Pages 7 & 8](#))

Future Meetings

Sep 3, Richard Lewellen, Music Therapist
[Sep 18, Picnic at Snook Memorial Park](#)
Oct 1, Dr. Joseph Savitt, Neurologist
Nov 5, Amanda Distefano, WCHD, Falls
Dec 3, Patients & Caregivers 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
Apr 7, Dr. Laxman Bahroo, Georgetown UMC
May 5, Attorney Michael G. Day, Elder Care
Jun 2, Patients & Caregivers Breakout Sessions
Jul 7, Candice Valencia, Trainer and Senior Yoga
Aug 4, Becky Dunlop, RN, BSN, Johns Hopkins

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
winchesterparkinsons@gmail.com
[Facebook.com/winchesterPDsupport](https://www.facebook.com/winchesterPDsupport)

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

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.

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Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3rd Monday of every month. In July, **Dave DeHaven, Mike Saterbak, Ecile Shaw, Linda Embly, Barb Harrell, Art Guyer and Carol Gaines** enjoyed breakfast and discussions together.

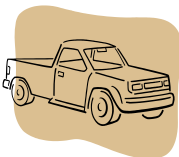
This month, our caregivers will meet for breakfast on Monday, August 17, at the **Hagerstown Family Diner** at 8:30 AM. This restaurant is located at 431 Dual Highway near the Best Western Grand Venice Hotel. Call Art if you need more information or directions.

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.

Respite Care is important for caregivers. You need a break every now and then. Respite care is substitute care given so the regular caregiver can take a break and get some relief from the burden of caregiving. Respite care can be for a weekend or a day or even for an hour, on a regular basis or just one time.

Sometimes respite care is given by family or friends, who want to relieve the regular caregiver of his/her burden. Or, it can be provided by paid caregivers.



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 Picnic



Our fall picnic this year is scheduled for Noon on **September 18** at the Martin L. Snook Memorial Park, Pavilion #4 in Hagerstown, MD. See [page 5](#) for details.

Contact Art to register.



Cards

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game. We will be playing on August 18th at the Guyer's home at 1:00 PM. Let's show some interest or we will not be inclined to continue this activity.

PD Group Bowling

Bowling has been put on hold due to other activities and the limited openings available at the bowling alley. We hope to resume next month.

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 August

Happy Birthday to our members who have August birthdays: **Bill Schumacher, Warren and Carol Leach, Charles Martin, Twila Flohr and Rodney Miller.**

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)

Keep Your Sense of Humor!



Having trouble walking, being unable to talk as loudly as you want, or giving up driving are not particularly funny. However, try to put a humorous spin on everyday observations and situations. For example, if you use a wheelchair, you might look at it this way: You always have a place to sit and a pair of shoes lasts you 30 years. Remember, laughter is a great stress reducer.

Participating in support group activities generally leads to some humorous situations and very often some telling of jokes and stories; our caring loving friends help us keep our spirits up.

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This and That Thoughts on my Mind by Art Guyer

Sandy Phillips shared this with me the other week. She found the service very helpful and very reasonable:

Good Guys Delivers Food To Your Home Or Office

David Walker opened Good Guys Restaurant Delivery in December. The business is a third-party restaurant delivery company. Customers contact them through their website or by phone to place food orders at select local restaurants that don't offer delivery. They pick up the food and deliver it to the customer's home in Hagerstown within 45 to 60 minutes for a \$6 delivery fee plus 15 percent tip. Pricing for outlying areas varies.

Address: 112 W. Howard St., Hagerstown, MD 21740

Hours: Monday to Saturday, noon to 8 p.m.

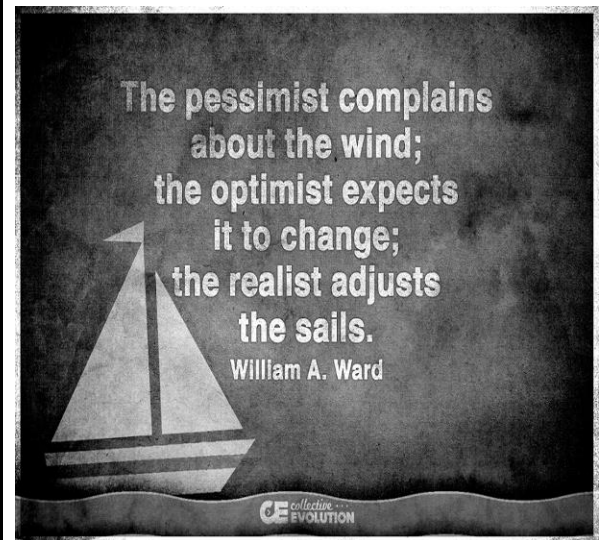
Phone number: 301-703-9363

Email: customerservice@goodguysmd.com

Website: www.goodguysmd.com

Facebook page: <https://www.facebook.com/goodguysrestaurantdelivery>

Take care..... Art



Approximately 1,000,000 people are living with Parkinson's in the U.S. Exercise helps people with Parkinson's improve their mobility.

Together, we will
Walk Off Parkinson's

September 13, 2015
Nationals Park, Washington, D.C.

1.5 mile walk ending with a victory lap on the field *plus* opportunity to take photos in the Nationals dugout

www.walkoffpd.org • (703) 734-1017

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Heads Up, Caregivers!

HOW CAN I HELP MANAGE MY LOVED ONE'S CARE? (Michael J. Fox Foundation Information)

Become an integral part of your loved one's experience with Parkinson's by offering to help share the responsibilities associated with the disease including doctor appointments, therapy sessions, medication administration, household duties or any activity that's more difficult to perform because of Parkinson's disease. People with Parkinson's will desire different levels of assistance and some wish to maintain as much independence as possible. You won't know if a person wants help unless you ask but then respect their response. Communication about these issues is key to understanding how best to help your loved one.

Ask your loved one if you can attend doctor's visits. Care partners play a major role on the team of people treating Parkinson's. You offer an outside view of how your loved one has been doing in the interim since the last visit. You may also recognize new symptoms or subtle changes that the person experiencing Parkinson's doesn't. For example, your loved one's mood or behaviors may have changed and he or she may be more withdrawn. These could be signs of depression, which is a clinical symptom of PD and is treatable with medication. A person with Parkinson's might otherwise dismiss this as a reaction to the diagnosis of PD or not even mention it to the doctor. You may also have noticed that your loved one's speech has become softer or more monotone. This may impact your ability to communicate and therefore your relationship. Speech therapists can prescribe exercises to improve voice control.

You and your loved one can decide together on management options offered and with two sets of ears tuning in, you can both be clear on the treatment plan. As a caregiver, keeping track of all the details associated with medical care can be overwhelming. Here are some tips to help:

Stay organized with a calendar that you can take on doctor visits. Note doctor and therapy appointments, start and stop dates of medicines, and any side effects you notice.

Keep a list of all doctors' phone numbers and addresses in case of an emergency. Keep a separate and updated list of all prescription medications, their dosages and instructions and prescribing provider. Note allergies or medication intolerances as well.

Familiarize yourself with the terms of your loved one's medical insurance. Know what services, including prescription medication coverage and therapy session benefits, are included. Talk with your physician about the long-term needs of your loved one, and make sure his or her current medical plan will meet those needs. Engage the services of a social worker if you need help navigating these issues.

Know your rights in terms of disability coverage, family leave and elder rights.

If possible, **consult a movement disorder specialist**, a neurologist specially trained in Parkinson's disease and other movement disorders. Before appointments, prepare a list of your questions for the doctor.

You do not need special medical training to help with any but the most advanced stages of the disease. Most caregivers are primarily called on to aid with daily tasks that may become difficult or impossible for someone with Parkinson's, and to provide ongoing emotional support. One exception: if Parkinson's Disease causes trouble swallowing and therefore increases the risk of choking, knowing the Heimlich maneuver can be life-saving.

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Fall Picnic 2015

Martin L. Snook Memorial Park, Pavilion #4, Hagerstown, MD

Date: **Friday, September 18, 2015**

Time: 12 PM Noon

Bring a covered dish or dessert and there will be fried chicken. We will provide drinks, eating utensils, and paper plates, cups, and napkins. The cost of the chicken and the fee for rental of the pavilion will be prorated to those attending. Historically, this has been about \$4 a person.

Thanks to Dean and Carol Cook, we will be having entertainment by *Act Two*, a duo comprised of *Ben and Connie Smith* who sing and "play" a variety of music with a county flavor. Come out and enjoy this rare opportunity



Ben and Connie Smith, Act Two

There will also be free bingo for all, as usual! Everyone should bring one or more wrapped, inexpensive "prizes" for bingo winners. Prizes can be something you want to get rid of or you can pick up some items from a "dollar



Ben and Connie Smith, Act Two

store." You can count on some guessing games too.

Directions:

For those using I-81, go East on I-70 at the I-81/70 Interchange

Eastbound on Interstate 70 (from I-81), take Exit 28, turn left on Downsville Pike; turn left at first traffic light. The park entrance is 100 yards past the light, on the left. Follow the park road to the end and the pavilion will be on the right.

Westbound on Interstate 70 (from Frederick), take Exit 28, the park entrance is 100 yards past the first stop light, on the left. Follow the park road to the end and the pavilion will be on the right.

For more information or to make reservations for the picnic, sign up at one of our meetings or contact:

Art Guyer
240-625-2722
4Parkinsons@gmail.com



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Diabetes Drug Trial Results are Disappointing

Michael J. Fox Foundation, July 2015

A diabetes drug that scientists thought may slow Parkinson's progression proved futile in a Phase II clinical trial, however this avenue of therapeutic pursuit is not closed.

A team from the National Institutes of Health (NIH) Exploratory Trials in Parkinson Disease (NET-PD) consortium recently published results from its randomized controlled trial (the gold standard) of treatment with one diabetes drug, *pioglitazone*. Ultimately the researchers concluded that pioglitazone at the doses studied is unlikely to modify progression in early Parkinson's disease.

In this study researchers tested pioglitazone in people with recently diagnosed PD by randomly assigning them to one of two doses (15mg or 45mg, representing the lower and higher ends of the dosage approved for diabetes) versus placebo. The study recruited 210 participants at 35 sites. Volunteers were followed for 44 weeks. Based on the analysis, neither dose of pioglitazone showed promise to be tested in further studies. The study did not have any significant safety concerns. Testing at high dosages of pioglitazone does not seem to be called for. One always has to balance tolerability and toxicity. In this case there is no objective rationale or safety comfort to move to a higher dose.

However, it does not mean that other diabetes drugs would have the same results. These findings leave the door open for other compounds working through the same pathways to potentially be efficacious. While the results of the study are disappointing, it is an important study and there is still rationale and justification to test other molecules targeting the same mechanisms of disease.

While researchers view diabetes drugs as a promising PD research approach, they discourage people with Parkinson's to explore use of diabetic drugs for treatment of PD today. People with PD should not attempt to use these drugs in absence of definitive data on efficacy and safety.

Parkinson's Diagnoses

Michael J. Fox Foundation

Parkinson's disease is often difficult to diagnose accurately, particularly when symptoms are mild. There is no simple diagnostic test, and approximately 25 percent of Parkinson's disease diagnoses are incorrect. Parkinson's disease starts out with such subtle symptoms that many physicians, who are untrained in it, fail to provide an accurate diagnosis. In fact, even the best neurologists can get it wrong.

It is recommended that unless your doctor is particularly experienced in this area, you should consult with **a movement disorders specialist**. A good neurologist will understand your desire for confirmation. If it is affordable (insurance doesn't always cover second opinions), and brings peace of mind, a second opinion can help you and your loved ones come to terms with your disease.

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Reminders of upcoming events as of Friday, August 07, 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 winchesterparkinsons@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
Frederick PD Support Group Monthly Meeting	3rd Wednesday @ 1:00 PM (Closed July and August) 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	Tuesday, August 18, 2015 @ 1:00 PM Art Guyer's Home	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	Times Vary 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:

- 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.
- 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.
- 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.
- Thursday, December 3, 2015 at 11:45 AM. Our regular monthly meeting will include breakout sessions and gift exchanges.

Remember! Our December meeting is on the 3rd and will feature small gift exchanges. Each person should bring a wrapped present that cost about \$5.00. Put this fun event on your calendar now. If someone would like to orchestrate one or more holiday games, contact me.



*My doctor asked if
any members of my
family suffered from
insanity...*

*I said nope, we all
seem to enjoy it!!*

Thanks, Betty Gladhill!