Hagerstown, MD and the Four-State Area

Monthly Newsletter

November 2015

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

Volume 5, Issue 11

Visit us on Facebook

Local Support Group Contacts

This Month's Meeting

November Meeting

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

See Page 3 for an article on Kiem Romsburg.

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

Western Sizzlin Steakhouse

MARK YOUR CALENDARS

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

We had 61 people at our October 1st meeting, including 7 guests and new members. It was a great crowd with a lot of questions for our speaker, Dr. Joseph Savitt, MD, PHD. Dr. Savitt is a practicing board certified Movement Disorder Specialist from the Parkinson's Disease and Movement Disorder Center of Maryland. He made an excellent presentation on PD, including symptoms, diagnosis, medication and treatment, and recently approved methods of delivery. He also highlighted a number of new treatments in testing. Dr.

17567 York Road, Hagerstown, MD Thursday, November 5, 2015, 11:45 AM

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

Our Speaker in November is

Friends in Frederick Parkinson's Support Group

Amanda Distefano from the Washington County Health Department On Falls and How to Prevent Them

Heads Up, Caregivers! (Page 4)

Fall Picnic Report (Page 5)

UMMC - MRI Focused Ultrasound (Page 6)

Detailed Event Listing (Pages 7 & 8)

Future Meetings

Dec 3, Patients & Caregivers Breakout Sessions

Nov 5, Amanda Distefano, WCHD, Falls

Janet Silvious, 301-831-5609, janet@fifpdsg.org or John Kraft, 301-845-6514, john@fifpdsg.org. www.fifpdsg.org

Parkinsons & Movement Disorders Ctr of MD 8180 Lark Brown Road, Suite 101

Frederick Parkinson's Disease Early Onset or Newly Diagnosed Community Support Group **Newsletter Highlights** Deb Bergstrom, Facilitator, 301-712-5381 or Tips for Making Life Easier (Page 3) dfbergstrom@comcast.net

Elkridge, MD 21075 Phone: 443-755-0031

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

Email: jsavitt@pdmdcenter.com Web URL: www.pdmdcenter.com

Savitt's contact information is:

oldred714@verizon.net Gettysburg Parkinson's Disease Support Group

Thanks to Mike Saterbak for asking the blessing. Nancy Melton won the \$10 gift certificate to the Western Sizzlin' Restaurant donated to the group by Paul Romsburg and his family.

Paula Chaplin, 717-337-4407, pchaplin@wellspan.org

Special Event in Winchester!

Attend a Support Group Meeting

On November 10, 2015, the Winchester Support Group will feature Nan Little, author of "If I Can Climb Mt. Kilimanjaro, Why Can't I Brush My Teeth?" - a new Parkinson's book. Meeting is at 11:00 AM at the Winchester Church of God, 2080 N. Frederick Pike, Winchester, VA. 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 Sep 1, Shelley Steiner, Hospice of Wash. County Oct 6. Dr. Kelly Mills. Neurologist from JHU Nov 3, Bailey Vernon, Johns Hopkins



Parkinson's Events Calendar On-Line.

The Hagerstown Parkinson's Support Group

The Hagerstown Parkinson's Support Group is supported in part by:

Dec 1 Patients & Caregivers Breakout Sessions

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



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 September, Dave DeHaven, Ecile Shaw, Mike Saterbak, Barbara Harrell, Art Guyer Peg Hayzlett, Helen Lockhard, and Gloria Rith enjoyed breakfast and discussions together.

This month, our caregivers will meet for breakfast on Monday, October 19, 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.



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.

ARE YOU A VET?

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Hospice of Washington County
Honors Veterans with a
Recognition Meal & Program On
November 7, 2015

Breakfast Lunch
Doors Open 7:45 Doors Open 11:15

A Free Meal to Each Veteran & Guest 747 Northern Avenue, Hagerstown, MD Call 301-791-6360 to Register

Bv October 31



Cards

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game. We are playing on October 20th at 1:00 PM. We need some players!

PD Group Bowling

Bowling started up last month and we had 13 members attending – Connie and John Hipp, Mike and Marci Saterbak, Dave and Patsy DeHaven, Doris and Art Guyer, Bill and Ruby Wilhide, Dean Cook, Faith Mattia, and Jon Pearson. We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes. In October we are scheduled to bowl on the 15th.

Call **Dave DeHaven** at 301-582-2815 for more information and directions.

Birthdays in October

Happy Birthday to the 19 members who have October birthdays. We sang happy birthday to you at our meeting this month.

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 to Keep a Positive Attitude. Even though it can be extremely difficult as your symptoms change and the effectiveness of medications plays havoc with your life, keeping a good attitude makes a world of difference to you and those around you. It's perfectly natural to mourn the loss of function and independence for a brief time, but try not to get stuck and wallow in self-pity and isolate yourself from friends.

If you experience a combination of these problems – loss of appetite, feelings of sadness, difficulty sleeping, loss of your sense of humor, a sense of hopelessness, or just feel down in the dumps – you may be suffering from clinical depression. Please! Tell your doctor. Even though you have every right to be depressed about your diagnosis, depression is a treatable condition. A combination of anti-depressants and/or psychotherapy can help lift your spirits and give you renewed energy to keep that all-important positive attitude.

Remember: Your family and friends are not trained professionals. In fact, they also may be hurting because of your diagnosis. Perhaps they, too, could benefit from talking to someone about their fears and frustrations.

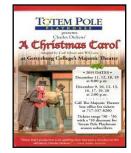
Listen to audiotapes and/or read books that promote positive thinking and deliver a healing message. The public library and bookstores offer an array of these materials. And <u>consider sharing this material</u> with others you feel could benefit who are in your support group.

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Totem Pole Playhouse

Speaking of positive activities, we will be making a trip to Gettysburg on **December 16th** at 2:00 PM to see the famous Charles Dickens' play, "*A Christmas Carol*." As a Totem Pole Playhouse subscriber I can get top tickets for \$28 each, a \$10 discount.

Please let me know if you want to join us. We will try to arrange car pools and have dinner afterwards someplace in the Gettysburg area.



A friend passes.....

As all of you are aware by now, long-time member Kiem Romsburg died on September 15th. Her obituary was published in the September 17th Herald-Mail and she was featured in a Life Remembered tribute on the paper on September 27th. In remembrance of Kiem, Paul and his sons treated the support group to a free lunch on October 1, 2015. The support group members at our fall picnic and our October meeting contributed more than \$250 to a Parkinson's service in Paul and Kiem's name. Frank McConnell took the lead in collecting and handling this fund and did a great job.

You can view the article at: http://goo.gl/DVYHLy



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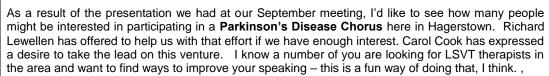
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Heads Up, Caregivers!

Management of a Parkinson's disease patient often extends beyond the physician and falls to a spouse, child, parent or friend.

- If the PD patient receives physical, occupational and/or speech therapy, make sure the recommended exercises are done regularly. Encourage your loved one to exercise as much as possible. Walking is a good exercise to start with.
- Make sure the loved one eats a balanced diet and maintains proper weight.
- If swallowing difficulties occur, your loved one should eat soft foods and take small bites. An electric warming tray will help keep food warm and minimize the need to rush.
- Learn the Heimlich maneuver. Your doctor can show you how to do it.
- If possible, enlist the help of a visiting nurse or health care professional.

This and That Thoughts on my Mind by Art Guyer





Please contact me if you would be willing to participate in this new effort. And take a look at the next article.

Take care Art

Music and Rhythm-Based Interventions for Parkinson's Disease

Exploration of Complimentary Therapies By Alexander Pantelyat, MD

Several music and rhythm-based therapies for Parkinson's disease have been explored in recent years. Some of the best evidence to date has been found for Argentine Tango. This ballroom dance involves big steps in multiple directions, and has been shown to significantly improve walking and balance in Parkinson's disease. It appears to have some additional benefits when compared with other ballroom dance forms such as Foxtrot. Also, when researchers compared traditional partnered Tango to non-partnered Tango, a similar degree of benefit for walking and balance was observed; however, those dancing alone found it less enjoyable, and therefore less motivating.

Argentine Tango has its origins in African rhythms, and Dr. Pantelyat recently studied group West African drumming (while seated) in 10 patients over 6 weeks. Compared to baseline, patients in the drumming group experienced a significant improvement in their overall quality of life, and also tended to walk faster after the drumming classes; this was not observed in the control group of patients who did not attend drumming classes.

The loss of voice volume and clarity is a common problem in Parkinson's disease, and several studies have evaluated the effects of singing in a choir on patient's voice quality and several other outcomes. While results so far have not been conclusive, the proliferation of Parkinson's disease choirs throughout the world and in the U.S indicates patients are experiencing benefits. A study of group choir-based singing for Parkinson's disease at Johns Hopkins (Parkinsonics) is about to get under way. The mechanisms of how these therapies work for Parkinson's Disease need to be investigated. What we know is that all of these interventions have in common a prosocial aspect, and are fun, thereby fighting isolation and motivating people to continue. Music and rhythm-based interventions are being actively evaluated at Hopkins. Please contact Becky Dunlop at 410-955-8795 to learn more.

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Fall Picnic 2015



On September 18th members and friends of the *Hagerstown Parkinson's Support Group* gathered for their fall picnic held at the *Martin "Marty" Snook Memorial Park* in Hagerstown, MD. The photo of the group was taken by Ms. Talia Valencia; the empty chair in the photo was in remembrance of **Kiem Thi Romsburg**, a long-time member of the support group, who passed on September 15th.

Picnic Attendees: Glenda Austin, Bill Baschke, Aura and Chuck Bihun, Carol and Dean Cook, Fred and Norma Craver, Harry and Phyllis Davis, David and Patsy DeHaven, Pat Donnelly, Linda and Paul R. Embly, Bill and Twila Flohr, Jackie Fouche, Art and Doris Guyer, Barbara and Jerry Harrell, Peg Hayzlett, Connie and John Hipp, Karen Kelly, Coreen and Marlo Ketchum, Jim and Lu Mattern, Franklin and Violet McConnell, Cheryl and Waverly Reames, Carl and Gloria Rith, Marci and Mike Saterbak, Ecile and Ragan Shaw, Ben and Connie Smith, Betty and Jay Stouffer, Michaela Whitaker, and Ruby and William Wilhide.

The lovely weather brought out 47 people to the event, a great turnout. They all enjoyed some wonderful food, bingo, guessing games, drawings for prizes, and a lot of excellent music. Thanks to Dean and Carol Cook for arranging to have their friends, Ben and Connie Smith play during lunch and perform a second set later in the afternoon. This variety music duo, known as ACT II, provided an afternoon of toe-tapping entertainment (www.acttwo.us). Joining them on occasion was member Carol Cook who belted out some great tunes also. In addition, member Marlo Ketchum joined in a number of times with his acoustic guitar. And at one point there were some members dancing – Peg Hayzlett and Carol Cook were caught on film doing the cha cha.

About 60 bingo prizes were given out; everyone playing bingo won at least one prize. Thanks goes to Dave DeHaven for arranging for the site and the fried chicken and for running the free bingo activity including calling the numbers. Others who helped with set up and other tasks during the event were Connie and John Hipp, Ragan and Ecile Shaw, and Frank and Vi McConnell.









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University of Maryland Medicine offers MRI-guided focused ultrasound treatment to Parkinson's patients

Source: University of Maryland Medical Center Published on September 2, 2015

University of Maryland Medicine and its Center for Metabolic Imaging and Image-Guided Therapeutics (CMIT) have begun to use MRI-guided focused ultrasound on a deep structure within the brain that is related to Parkinson's disease.

In the first clinical trial of its kind, researchers from CMIT are using magnetic resonance imaging (MRI) to guide ultrasound waves through the intact skin and skull to the globus pallidus. The University of Maryland is one of only two sites in the United States to offer this treatment to Parkinson's patients.

The globus pallidus contributes to the regulation of voluntary movements and is targeted with medications and, in advanced cases, deep brain stimulation using implanted micro-electrodes to treat motor symptoms of tremor, rigidity and dyskinesia in patients with Parkinson's. Dyskinesia (abnormal, distorted movement) is a common side effect of the medication levodopa that can affect quality of life for patients with Parkinson's.

Principal investigator Howard M. Eisenberg, MD, states the utilization of MRI-guided focused ultrasound could help limit the life-altering side effects like dyskinesia to make the disease more manageable and less debilitating.

Using advanced focused ultrasound technology, surgeons can now apply microscopic sound waves to precisely target diseased regions deep within the body without incisions or radiation. Functional imaging and non-invasive ultrasound procedures are done on an outpatient basis in the CMIT MRI suite. During the Parkinson's procedure, patients lie in an MRI scanner with a head-immobilizing frame fitted with a transducer helmet. Ultrasonic energy is targeted through the skull to the globus pallidus of the brain, and images acquired during the procedure give physicians a real-time map of the area being treated. "We're raising the temperature in a very restricted area of the brain to destroy tissue," Dr. Eisenberg said. "The ultrasound waves create a heat lesion that we can monitor through MRI."

The entire procedure lasts two to four hours, and patients are awake and able to interact with the treatment team. This allows the physicians to monitor the immediate effects of treatment and make adjustments if necessary. The clinical study builds on experience gained during a pilot trial that investigated focused ultrasound for patients with essential tremor.

Note: Kim Spletter is the first person to have MRI-Focused Ultrasound to treat Parkinson's disease. She recently underwent the procedure at the University of Maryland Medical Center. She talked about her experiences at the Frederick Parkinson's Support Group September meeting. Find out more at links on their page at: http://fifpdsg.org/.



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Reminders of upcoming events as of Friday, October 02, 2015

REGULAR EVENTS:

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 st Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 st Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Shirley McKinney, 301-729-1427 sjmckinney@atlanticbb.net
Winchester PD Support Group Monthly Meeting	2 nd 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 nd 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 rd Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Frederick PD Support Group Monthly Meeting	3 rd Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 rd Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
Frederick County Parkinson's Early Onset or Newly Diagnosed Community Support Group	3 rd Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 dfbergstrom@comcast.net
Berkeley County Parkinson's Support Group	4 th Wednesday @ 6:30 PM Otterbein United Methodist Church, Martinsburg, WV	Debi Corbin, 304-886-8594 danicasgma@aol.com

OTHER EVENTS:

- October 14, 2015, 1:30 PM: Central PA Parkinson's Support Group Meeting in Mechanicsburg, PA. Bob Lindsay will be the speaker.
- NEW! Parkinson's Disease Community Educational Series 3rd Wednesday of EVERY month (October 2015 December 2016), 7:00 p.m. 9:00 p.m. St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD 21093 October 21: Research Update (Panel) Register November 18: Management of Non-Motor Symptoms (Dr. Howard Weiss) Register December 16: Fall Prevention (Dr. Stephen Grill) Register Contact Bailey Vernon at 410-616-2811.
- <u>Friday, October 23, 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.
- Thursday October 29, 2015, 10:00 a.m. 2:00 p.m.: Support Group Leader Networking Meeting, St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD 21093

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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.
- Tuesday, November 10, 2015, 11:00 AM: Winchester Parkinson's Support Group Meeting. The speaker is Nan Little, author
 of "If I Can Climb Mt. Kilimanjaro, Why Can't I Brush My Teeth?"
- Wednesday, December 16, 2015, at 2:00 PM: Totem Pole Playhouse Presents "A Christmas Carol" at Gettysburg College's Majestic Theater. Call Art at 240-625-2722 or email 4Parkinsons@gmail.com for information and discounted tickets.

<u>2016</u>

• <u>Saturday, March 19, 2016 at 8:00 AM – 4:00 PM</u>. 2016 PFNCA Symposium at the Fairview Park Marriott in Falls Church, VA. Registration opens in January 2016. Call 703-734-1017 for more information.

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.



-----Cut Out and Save-----

Hagerstown Parkinson's Support Group 2016 Speaker Schedule

Date	Speaker
January 7	David Kukor, Accessible Home Care
February 4	Cathy Hanson, Alzheimer's Association
March 3	Michelle Cines, RN, University of Maryland Medical Center
April 7	Dr. Laxman Bahroo, Neurologist, Georgetown University Medical Center
May 5	Attorney Michael G. Day, Elder Care
June 2	Patients & Caregivers Breakout Sessions
July 7	Candice Valencia, Personal Trainer, Senior Yoga and Strength Training
August 4	Becky Dunlop, RN, BSN, Johns Hopkins Movement Disorder Center
September 1	Shelley Steiner, Hospice of Washington County
October 6	Dr. Kelly Mills, Neurologist, Johns Hopkins Movement Disorder Center
November 3	Bailey Vernon, Community Educator JH Movement Disorder Center
December 1	Patients & Caregivers Breakout Sessions