

# The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

## Monthly Newsletter

July 2014

Visit Our Website at:  
[www.fareshare.net/Parkinsons/](http://www.fareshare.net/Parkinsons/)

[Visit us on Facebook](#)

Volume 4, Issue 7

### This Month's Meeting

We had 47 attendees at the June meeting, including 3 new members who joined us for the first time. We'd like to welcome **Barbara Bittorf** and **Bill and Ruby Wilhide**. We hope you return often.

Our surprise guest speaker was **Bob Teufel** who called me several weeks back and volunteered to come down from Elizabethtown, PA where he lives with his wife of 52 years, Jean. They have 4 daughters and 10 grandchildren. Bob ran a Prosthetic & Orthotic business for 40 years in South Central Pennsylvania, including the Chambersburg area. He retired to fish and play golf in 2002. In 2004 he was diagnosed with PD. He still plays a lot of golf and fishes frequently.

Bob has figured out how to live more comfortably with PD and shared his discoveries with us. He has a great sense of humor and laced his presentation with jokes along the way.

He brought a large selection of pill boxes so we could get an idea of what's available in the market. He showed us a seat belt extension that is available to make buckling up easier. Bob showed us a golf club that has made his putting better and a special golf tee that is easier to use than the standard one. He also told us he uses a mixture of bran cereal, apple sauce, and prune juice for bowel regularity. He combines one cup of each and stores it in the refrigerator, taking a tablespoon a day at first. Increase the amount over time if it does not work at first.

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### July Meeting

#### MARK YOUR CALENDARS

Join us for our next  
**Parkinson Support Group Meeting**  
at the  
**Western Sizzlin Steakhouse**  
17567 York Road, Hagerstown, MD  
(301) 791-7560

Thursday, July 3, 2014, 11:45 AM

Our July Speaker is  
**Bailey Vernon, MPH, CHES**  
Health Educator  
Parkinson's Disease & Movement  
Disorders Center, Johns Hopkins

#### Highlights

[Inhaled Levodopa \(Page 3\)](#)  
[MJ Fox Research Study \(Page 4\)](#)  
[Summer Picnic \(Page 5\)](#)  
[Self-Care Tips \(Page 6\)](#)

### Attend a Support Group Meeting



### Upcoming Events

#### Future Meetings

July 3, Bailey Vernon, JHM Health Educator  
August 7, Becky Dunlop, JHM Nurse Coord.  
September 4, Dr. Paul Dash, JH Neurologist  
October 2, Doug DeHaven, Fire Marshall  
November 6, Stephen Ryan, Physical Therapist  
December 4, Breakout Sessions

#### Educational and Other Activities

##### Caregivers' Breakfast:

Third Monday of every month, 8:30 AM at the Railroad Junction Family Restaurant. June's breakfast is on the 16th.  
Call Art Guyer for information.

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#### Other Local Support Group Contacts

Berkeley County Parkinson's Support Group  
Debi Corbin, Facilitator, 304-886-8594  
[danicasgma@aol.com](mailto:danicasgma@aol.com)

Winchester Area Parkinson's Support Group  
Sharon Wilson, Facilitator, 304-258-0496  
[sharonjfk50@frontier.com](mailto:sharonjfk50@frontier.com)  
<http://www.walkrunmove.org/>  
[Winchester Facebook Page](#)

Cumberland Parkinson's Support Group  
Shirley McKinney, Facilitator, 301-729-1427  
[sjmckinney@atlanticbb.net](mailto:sjmckinney@atlanticbb.net)

Chambersburg Parkinson's Support Group  
Warren Leach, 717-264-2908  
[SKIPL815@AOL.COM](mailto:SKIPL815@AOL.COM)

Frederick PD Support Group  
John Kraft and Janet Silvious, Facilitators  
301-845-6514  
[janet@fifpdsg.org](mailto:janet@fifpdsg.org)  
[www.fifpdsg.org](http://www.fifpdsg.org)

The Hagerstown Parkinson's Support Group

Group Facilitator:  
Art Guyer  
22215 Troy Lane  
Hagerstown, MD 21742  
240-625-2722  
[aguyer42@myactv.net](mailto:aguyer42@myactv.net)

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



17567 York Road Hagerstown, MD  
Stop by for lunch or dinner to support them!

Thanks to Paul Romsburg, his family, and staff of the *Western Sizzlin* for supporting our group.

**UNSUBSCRIBE:** If you no longer wish to receive this newsletter, please contact the Group Facilitator, Art Guyer.

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### Caregiver's Breakfast.

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month. In May, **Mike Saterbak, Ecile Shaw, Barbara Harrell, Peg Hayzlett, Dave DeHaven, Dick Naugle, and Art Guyer** enjoyed the Caregivers' Breakfast.

This month, caregivers will meet for breakfast on June 16, at the Railroad Junction Family Restaurant, at 8:30 AM. The restaurant is located at 301 S. Burhans Blvd E, in Hagerstown.

You are encouraged to participate if possible. It gives caregivers the opportunity to seek advice in a safe environment and it allows feedback for future meetings and activities.



### Birthdays in June

Happy Birthday to 8 of our members who have June birthdays: **Debbie Dieterich, Carl Rith, Judith Miniter, Jack Nazelrod, Richard Hult, Peggy Naugle, Pam DeGrange, and my high school sweetheart, Doris Kirkpatrick 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!

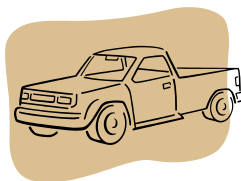


### Need Transportation or Just a Break?

Remember, if you need transportation to our meetings or other events, please let us know.

If you would like a couple of hours of free time and we can take your spouse for a short day trip, we will be happy to try to work something out for you.

Give Art a call or send him an email.



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### In The Hospital?

If you or your spouse, or a member you know is not doing well and/or is in the hospital, please let us know. We like to visit our friends when possible. **Barb Harrell has volunteered as the Sunshine Committee of One** and will be responsible for sending out cards as appropriate. Call her at 301-797-7845 or contact Art if you know someone in need.

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### PD Group Bowling

On Thursday, June 26<sup>th</sup> at 1:00 PM we will have our first "PD Bowling Event." It will be at Southside Bowls at 17325 Virginia Avenue in Hagerstown. The alleys will be set up for those who have difficulty moving, lifting or even walking. Get some exercise! Call Dave DeHaven at 301-582-2815 for more information and directions.

### Upcoming Events (Cont. from Page 1)

**Johns Hopkins Educational Seminars**  
*(Registration is required for all):*

#### **An Educational Series for Individuals Newly Diagnosed with Parkinson's**

A 3-session educational opportunity for newly diagnosed Parkinson's patients and their families. To be held at Lutherville, MD. Registration is required and the cost is \$20 per person. Contact Bailey Vernon at 410-616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu).

Monday, June 16, 2014

Monday, June 23, 2014

Monday, June 30, 2014

#### **Deep Brain Stimulation Information**

**Session:** A session on the innovative technique to provide relief for people with Parkinson's Disease. To Register call 410-616-2811.

Monday, Sept. 8, 2014 6:00 PM - 8:00 PM

For more information on these JHU events, contact **Bailey Vernon** at 410-616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu).

### June 20 Picnic

On June 20<sup>th</sup> we will be holding our first picnic of the year. If you would like to attend, please contact Art by June 16<sup>th</sup> so we can order the right amount of chicken.



[See Page 5 for details and directions](#)

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### Positive Results For CVT-301

Civitas Therapeutics recently announced positive results for CVT-301, inhaled levodopa for the treatment of Parkinson's Disease (PD). CVT-301 is in a Phase 2 clinical trial and it was demonstrated that it is safe and well tolerated by Parkinson's patients. Inhaled levodopa is being developed to provide Parkinson's patients with relief from debilitating motor fluctuations, known as Off episodes. Further testing is required to determine future developments as this enters Phase 3 trials.

#### THE UNMET NEED

The unreliability of available medications for symptomatic treatment of PD remains a significant unmet need. Even when treated with the current standard of care, the majority of PD patients continue to experience motor fluctuations where the symptoms return rapidly and unpredictably. These unpredictable OFF episodes reduce patients' ability to lead productive, independent lives and are recognized by patients, care givers and healthcare professionals as one of the most troubling and debilitating issues associated with the disease.

L-dopa remains recognized as the most effective and widely used treatment for PD symptoms in spite of this intrinsic unreliability. Oral L-dopa is administered to maintain dopamine levels in the brain above the therapeutic threshold; however, the effectiveness of oral L-dopa formulations is significantly compromised by delayed and unpredictable absorption resulting in OFF episodes.

#### FOR CONSISTENT AND RAPID RELIEF FROM DEBILITATING OFF EPISODES

CVT-301 is being developed as adjunct, on-demand therapy to standard oral L-dopa therapy to address OFF episodes as they emerge and enable patients to reliably manage their symptoms. By delivering L-dopa through the pulmonary route, it is anticipated that CVT-301 will consistently, rapidly and precisely increase the patients' L-dopa plasma levels to alleviate sudden and unpredictable OFF episodes and bridge them to their next scheduled dose of oral medication. The ease of use of a simple inhaler will allow patients to use CVT-301 wherever and whenever their oral Parkinson's medications begin to fail them.

CVT-301 clinical studies conducted to date have been funded in part by grants from The Michael J. Fox Foundation for Parkinson's Research.

### Other Stuff

- **The Frederick PD Support Group has invited us to join them for their picnic on Wednesday, June 18<sup>th</sup> at 1:00 PM. Contact Janet Silvius at 301-831-5609 for information.**
- **If you want to attend the Totem Pole presentation of "Ring of Fire, the Johnny Cash Musical" on Wednesday July 2<sup>nd</sup> at 3:00 PM, contact Art for discount tickets and other information.**
- **Card Players! We are playing on Friday, June 13<sup>th</sup>. If you are interested, call Dave DeHaven at 301-582-2815**
- **Partners in Parkinson's Seminar. Save this date: Sunday, October 12, 2014, in Washington, DC. Information and registration on this website: <https://www.partnersinparkinsons.org>.**

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### DO YOU HAVE MILD TO MODERATE PARKINSON'S DISEASE?



If you are 35-70 years old, you may be eligible for a medical research study sponsored by The Michael J. Fox Foundation for Parkinson's Research. You must have a PD diagnosis for 10 years or less and have been 30 years old or older at the time of diagnosis. Women must be postmenopausal or surgically sterile.

#### What is the goal of this study?

To assess the safety and tolerability of an oral medication administered over 14 days. The compound is being tested for its effect on cognition in PD.

#### What is involved if I participate?

The study involves an initial overnight inpatient stay. You will be sent home with additional doses of the study drug and, over the course of the study, take medication over a range of 20-33 days. Then, there will be either 1 or 2 additional overnight inpatient stays, plus outpatient visits and follow-up phone calls.

#### Will I be compensated for participation?

Participants receive study procedures at no cost. You will be compensated \$1,350-\$1,775, depending upon the part of the study in which you participate.

Please contact us:

1-800-797-2448

[www.PAREXEL.com/baltimore](http://www.PAREXEL.com/baltimore)



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### Summer Picnic

**When:** Friday, June 20, 2014, 12 Noon

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

Bring a covered dish or dessert and there will be fried chicken.

There will be free bingo for all! 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 store."

#### 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 left.

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, contact Art by phone at 240-625-2722 or email at [aguyer42@myactv.net](mailto:aguyer42@myactv.net) by June 16<sup>th</sup>.**

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#### June Meeting (Continued from [Page 1](#))

Bob also showed some tennis shoes that had been re-soled with leather to help them slide on carpet. This prevents the "sticking" effect of rubber that usually occurs with some shoes. One of our members even tried them on and walked around – he loved them! (No names of course!) The work has to be done by a shoe repair shop. I did an internet search for cobblers in the area and came up with these possibilities.

- Cobblers Bench Shoe Repair, 5500 Buckeystown Pike, Ste 622, Frederick, MD 21703, (301) 620-9200
- Shoe Doctor, 625 W Washington St., Hagerstown, MD 21740, (301) 739-8777
- Eby's Shoe Repair, 17323 Reiff Church Rd, Hagerstown, MD 21740, (301) 797-7959
- Nemzek's Modern Shoe Repair, 51 W 2nd St., Waynesboro, PA 17268, (717) 765-4595
- Rob's Shoe Repair & Orthotic, 1938 Lincoln Way East, Chambersburg, PA 17202, (717) 496-3406



We enjoyed Bob's presentation including all of his jokes and tips.

I want to thank **Dick Naugle** for his humorous reading and for asking the blessing.

**The Matterns** won the \$10 gift certificate to the Western Sizzlin Restaurant donated by **Paul Romsburg** and his family. Paul also donated 3 bottles of steak sauce that was given away by raffle.

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### Steps to Self-Care and Wellness

1. **Examine your values.** Do what's important to you. Don't sweat the small stuff. Get the leisure time you need to avoid burnout. Use goals for daily living.
2. **Build yourself up.** Have positive 'self-talks.' Discipline yourself not to overreact emotionally to stressful situations. Anticipate life change events and plan for them in advance if possible. Affirm your value.
3. **Learn to relax.** Meditate. Listen to soothing music. Breathe deeply and block out the world twice a day for 15 minutes or so. Pace yourself and give yourself time to recharge.
4. **Exercise regularly.** Three to four times a week for 30-60 minutes a session.
5. **Eat sensibly.** Maintain your normal weight with a low-fat, high carbohydrate diet (or follow the most recent recommendations of health professionals).
6. **Avoid chemical solutions.** Stop smoking. Avoid caffeine. Limit your alcohol and avoid other drugs.
7. **Take control of your life.** Maintain a sense of humor. Delegate responsibility and combat perfectionism. Resist unreasonable demands on your time. Spend time with your family. Nurture your friendships and do things you enjoy. Always keep one foot in something comfortable. Live through your values.

