Hagerstown, MD and the Four-State Area

Monthly Newsletter

June 2014

This Month's Meeting

We had 51 attendees at the May meeting, including 5 new members.

Our speaker was Kylie Osman, Speech Therapist, who gave an excellent presentation describing (1) when to see a speechlanguage pathologist if one is having problems with speech, swallowing, voice, or even memory or thinking (2) compensatory strategies for PD patients in these same categories, and (3) tips for family members and friends of persons with PD.

Tips include: Looking at each other when speaking; reduce background noise; don't assume your message is understood; be concise and use short sentences; stick to the topic; offer options when asking for a choice; review upcoming activities daily; write down important information; and keep to a routine. **Ask Art for contact info**.

I want to thank **Dick Naugle** for his inspirational reading and for asking the blessing. It was wonderful having Dick and Peggy back at a meeting again after he spent so much time in the hospital.

The Kaisers won the \$10 gift certificate to the Western Sizzlin Restaurant donated by **Paul Romsburg** and his family.

FRIENDS ARE LIKE WALLS. SOMETIMES YOU LEAN ON THEM AND SOMETIMES IT'S GOOD JUST KNOWING THEY ARE THERE.

Anurag Prakash Ray

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

Visit us on Facebook

May 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, June 5, 2014, 11:45 AM

Breakout Sessions!

Highlights <u>Spinal Stimulation (Page 3)</u> <u>PD Triggers and Treatment (Page 4)</u> <u>Summer Picnic (Page 5)</u> <u>PD and Pesticides (Page 6)</u>

HPSG Caregivers' Breakfast

Third Monday of every month, 8:30 AM at the Railroad Junction Family Restaurant in Hagerstown. May's breakfast is the 19th. Call Art Guyer for information.

June Picnic

Be sure to sign up for the HPSG picnic to be held on June 20, 2014. Call or email Art to register or sign up at the June Meeting. See Page 5 for details.

Volume 4, Issue 6

Upcoming Events

Future Meetings

June 5, Breakout Sessions

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

Attend a Support Group Meeting

Other 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 Sharon Wilson, Facilitator, 304-258-0496 <u>sharonjfk50@frontier.com</u> <u>http://www.walkrunmove.org/</u> <u>Winchester Facebook Page</u>

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

Chambersburg Parkinson's Support Group Warren Leach, 717-264-2908 <u>SKIPL815@AOL.COM</u> Kathy Smith, 717-263-3524 <u>Kathy.Smith@embarqmail.com</u>

Frederick PD Support Group John Kraft and Janet Silvious, Facilitators 301-845-6514

janet@fifpdsg.org 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 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, **Mike Saterbak, Ecile Shaw, Barbara Harrell, Peg Hayzlett, Dave DeHaven, Sandy Phillips, and Art Guyer** enjoyed the Caregivers' Breakfast.

This month, caregivers will meet for breakfast on May 19, 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 May

Happy Birthday to 7 of our members who have May birthdays: Robert Dieterich, Melody Gearry, Dia Schumacher, Clift Smith, Elizabeth Malek, Leona Watson, and of course, yours truly.

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.



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.



Photo by Amy Kelley WHAG interview at our Seminar on April 4, 2014.

June 2014

Upcoming Events

Caregiver's Breakfast

Monday, May 19, 2014 8:30 AM See first column on this page for details.

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 <u>bvernon1@jhmi.edu</u>. Monday, June 16, 2014 Monday, June 23, 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 <u>bvernon1@jhmi.edu</u>.

Physical & Occupational Therapy for PD: Science & Practice of LSVT BIG ™ Sunday, June 1, 2014 Free seminar in Winchester, VA. Call 520-867-8838 to register. See Page 3 for more details.

HPSG Picnics Friday, June 20, 2014 See Page 5 for details.

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Leave the Brain Out of It: Spinal Stimulation Could Offer an Alternative to Treat Parkinson's Motor Symptoms

Michael J. Fox Foundation: Maggie McGuire, March 10, 2014

Deep brain stimulation (DBS) is a game changer for many Parkinson's disease (PD) patients. This therapy can alleviate motor symptoms and improve quality of life, but it does require brain surgery and is not a possibility for all people with PD. A group of researchers from Duke University and the Edmond and Lily Safra Institute of Neuroscience of Natal in Brazil is working toward the same end result without the need for such an invasive procedure. These investigators have published in a report that spinal cord stimulation in pre-clinical models improved motor symptoms and showed neuronal protection.

The Michael J. Fox Foundation (MJFF) did not fund that study, but did fund research from this same group of investigators to test spinal stimulation in a more advanced model. The MJFF-supported study is not testing the neuroprotective effect.

"This is an exciting time for, what we call, neuro-modulation," says Maurizio Facheris, MD, MSc, Associate Director of Research Programs at MJFF. "While deep brain stimulation has helped many people living with Parkinson's disease, there are limitations to its use. Spinal stimulation could extend this therapeutic approach to many more."

For DBS, a surgeon implants a thin electrode into the brain, targeting motor circuits that are not functioning properly. Small electrical pulses from a device similar to a cardiac pacemaker block the signals that cause some PD motor symptoms. Spinal stimulation uses the same technique, but rather than blocking the signals where they begin, the therapy blocks them further downstream. The electrodes are implanted in the dura, the outermost of three layers that surround the spinal cord.

Spinal cord stimulation is already used to treat chronic pain. Researchers are fine-tuning the application to work on the neurons that misfire to create Parkinson's motor symptoms. If successful, this procedure would be an alternative for patients who may not be able to have DBS because of vascular problems, mood disorders or aversion to brain surgery.

Physical & Occupational Therapy for Parkinson Disease: The Science and Practice of LSVT BIG[™]

Symposium at the Shenandoah University - Brandt Student Center 1460 University Drive, Winchester, VA 22601 Sunday, June 1, 2014, 12:30 – 2:30 PM

You are invited to attend a free two-hour interactive symposium on movement disorders and physical and occupational treatment for people with Parkinson disease (PD).

The symposium will include a 1-hour lecture presented by world experts in physical/occupational therapy for people with Parkinson Disease. This lecture will be followed by an interactive session where participants with PD are invited to interact with physical or occupational therapists practicing Parkinson-specific movement exercises (LSVT BIG). Please wear comfortable clothing to the event.

RSVP to LSVT Global at: 1-888-438-5788 or 1-520-867-8838 or by email at: info@LSVTGlobal.com Visit the LSVT website at <u>http://www.lsvtglobal.com</u> for more information

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FDA Approves Vanderbilt Trial For Parkinson's Treatment

Tom Wilemon, twilemon@tennessean.com 10:12 p.m. CDT April 4, 2014

Parkinson's disease researchers at Vanderbilt University have gotten the go-ahead from the U.S. Food and Drug Administration to expand a trial of a new treatment using deep brain stimulation.

The phase III trial will recruit 350 patients at 15 academic medical centers in the United States and Europe, according to a press release issued by Vanderbilt University Medical Center.

"This research has been decades in the making, and we are so excited to receive this approval to expand the trial," said Dr. David Charles, the chief medical officer of the Vanderbilt Neuroscience Institute. "Our hypothesis is that patients who have deep brain stimulation applied in the very early stage of Parkinson's disease will do much better in quality of life and motor function and have delayed onset of disability and medication-associated complications. Expanding the trial will help test that hypothesis."

Parkinson's disease is believed to affect as many as 7 million people worldwide, according to the press release.

To learn more about the trial, contact Vanderbilt University Medical Center at 615-343-2961.

Researchers Identify Biological Process That Triggers Parkinson's Disease

By Nicole Kwan Published April 10, 2014 FoxNews.com

New research has identified a biological 'trigger' for Parkinson's disease. The findings, published in the journal Cell, may lead the way to early diagnostic tools and treatments that could shut down the disease before symptoms progress in patients. Using both human neurons and fruit flies, researchers at Johns Hopkins have identified a protein, s15, that triggers a common form of Parkinson's disease. The protein is enabled by an enzyme - Leucine-Rich Repeat Kinase 2 (LRRK2) - which then causes neurodegeneration.

Previous research has shown that mutations in LRRK2 are linked with neurodegeneration, and therefore, the progression of Parkinson's disease. LRRK2 had been previously identified to be a type of enzyme that adds phosphates on to other proteins and either turns proteins on or off or changes the protein's activity. However, the proteins LRRK2 was acting on were unknown—until now. "How mutations in [LRRK2] cause Parkinson's disease aren't well known, and what this study does is provides a pretty convincing set of data on how mutations in LRRK2 cause Parkinson's disease," study author Dr. Ted Dawson, Professor of Neurology and Director of the Johns Hopkins Institute for Cell Engineering, told Fox News.

The study's findings suggest that inhibiting s15 and LRRK2 could prevent the loss of dopamine neurons and the onset of Parkinson's disease. LRRK2 inhibitors exist, but have not been tested in patient trials. Studies are needed to identify inhibitors of s15, Dawson said.

Currently, the drug levodopa is used to treat the symptoms of Parkinson's. While effective, it doesn't treat all the symptoms, has side effects and doesn't prevent degeneration. Researchers hope their study of LRRK2 could lead to an earlier diagnosis and better treatments for Parkinson's. "The general idea now is that ... the degenerative process is starting many, many years before people start to manifest with symptoms," Dawson said. "Once we do have [medications] that slow the progression, there are people who have [mutations in LRRK2] who you'd think would want to know and would want to take it."

Development of consumer-ready drugs could take years; Dawson estimated 3 to 5 years for LRRK2 trials with patients and another 10 years for s15 inhibitors.

"If you look at neurodegenerative diseases, they're a major and substantial health problem for the U.S. and it's only going to get worse, but the U.S. is not investing the required resources to really make substantial headway into treating not only Parkinson's but other neurodegenerative disorders," Dawson said.

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Summer Picnic

Date: Friday, June 20, 2014

Time: 12 PM

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

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

The cost of the chicken and the fee for rental of the pavilion will be prorated to those attending.

There will be free bingo for all! Everyone should bring one or more <u>wrapped</u>, <u>inexpensive</u> <u>"prizes</u>" 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 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, contact:

Art Guyer 240-625-2722 aguyer42@myactv.net

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Parkinson's Disease and Pesticides: What's the Connection?

Scientists find a way chemicals may contribute to Parkinson's Scientific American | Apr 8, 2014 | By Bret Stetka

What exactly causes Parkinson's disease is far from figured out. But a clue has been lurking in cornfields for years.

The data confirm it: farmers are more prone to Parkinson's than the general population. And pesticides could be to blame. Over a decade of evidence shows a clear association between pesticide exposure and a higher risk for the second most common neurodegenerative disease, after Alzheimer's. A new study published in Neurology proposes a potential mechanism by which at least some pesticides might contribute to Parkinson's.

Regardless of inciting factors — and there appear to be many — Parkinson's ultimately claims dopamine-releasing neurons in a small, central arc of brain called the "substantia nigra pars compacta." The nigra normally supplies dopamine to the neighboring striatum to help coordinate movement. Through a series of complex connections, striatal signals then find their way to the motor cortex and voila, we move. But when nigral neurons die, motor function goes haywire and the classic symptoms set in, including namely tremors, slowed movements, and rigidity.

Pesticides first came under suspicion as potentially lethal to the nigra in the early 1980s. In 2000, a meta-analysis linked confirmed and presumed pesticide exposure with increased risk of Parkinson's. Subsequent work supported this connection, including a large 2006 study that followed patients for nine years. The patients exposed to pesticides had a 70% higher incidence of Parkinson's when the study ended; the risk was the same for exposed farmers and exposed non-farmers, hence some other farm-related factor wasn't to blame.

The new study, from a team at UCLA, proposes a mechanism by which some pesticides might contribute to Parkinson's. It might also provide a major lead in understanding the disease. The findings not only point to new culprit compounds, but reflect the growing appreciation of Parkinson's as a multifactorial disease, in many cases due to the collusion of both genetic and environmental factors.

At least 10% of Parkinson' cases are now thought to be due primarily to specific gene variants, and estimates suggest that genetics may contribute to upwards of 20% to 50%. Patients with a few specific mutations — common in people of Mediterranean descent — carry a nearly 100% chance of developing the disease. Though, as lead author Dr. Jeff M. Brontstein commented to Scientific American, while a minority of cases might be primarily due to a specific genetic or environmental risk factor, ultimately many if not most cases are likely due to gene-environment interactions. This may explain why there isn't an epidemic of Parkinson's in rural areas. Despite the large number of people regularly exposed to pesticides, not everyone has a genetic susceptibility.

Recent evidence positions Parkinson's as one of a number of related neurodegenerative disorders marked by the accumulation of abnormal proteins in the brain, including Alzheimer's disease and ALS. They all appear partially genetic, partially environmental and probably in many cases both.

The new findings further confirm that those whose livelihood relies on repelling pests should pay mind to their increased risk for Parkinson's, particularly if they have other known risk factors, and take precautions. Rarely are neurologic diseases straight forward, and Parkinson's has proved no different. But a terribly unfortunate outcome for many in search of heartier, healthier crops may have brought medicine one notch closer to deciphering a frustratingly complex disease.

Edited Version: Full On-line Version is at: http://www.scientificamerican.com/article/parkinsons-disease-and-pesticides-whats-the-connection/