

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

March 2013

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

[Visit us on Facebook](#)

Volume 3, Issue 03

February Meeting Highlights

We had 37 attendees at our February meeting, including 5 new individuals.

Kathy Fisher, Manager of the Washington County Senior Center @ Girls, Inc. was our speaker. She discussed the many programs at the Center and how they are helpful to seniors, especially those with Parkinson's disease. Kathy also briefly discussed the status of the Center's location change. She indicated they expect to move to a temporary location this summer.

Dick Naugle asked the blessing and everyone enjoyed the food and conversation at the tables.

I want to thank all of you who made cash contributions at the meeting to help offset the cost of sending out our newsletters and other expenses. It was very generous and helps a lot!

Thanks from Peg!

Doris and I talked to **Peg Hayzlett** last week and she wanted us to pass on her thanks to all of you who called or sent cards when Huck passed. She is doing well and has been traveling to be with or see family.

Mike and Marci Saterbak and Dick and Peggy Naugle are all improving and were able to attend out meeting this month.

Thanks also to **Paul Romsburg**, his family, and staff for supporting our group. They have done a great job in providing us a place to meet and a great lunch.

The Hagerstown Parkinson's Support Group Contact

Group Facilitator, Art Guyer:
Phone: 240-625-2722
E-mail: aquyer42@myactv.net

March 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, March 7, 2013, 11:45 AM.

Remember our winter meetings will take place unless the Washington County School System closes for the entire day.

Our Speaker in March will be
Dr. Liana Rosenthal, John Hopkins Movement Disorder Center

New Parkinson's Treatments
See Page 3
Legal Issues Behind Caregiving
See Page 4

Totem Pole Playhouse Event:

If you want to join a few of us at the Totem Pole Playhouse to see "A Closer Walk with Patsy Cline," on Wednesday, June 19th, at 2:30 PM, contact the Box Office toll free at: 888-805-7056

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



17567 York Road Hagerstown, MD
(301) 791-7560

Stop by for lunch or dinner to support them!

Upcoming Events

Future Meetings

March 7, Dr. Liana Rosenthal, JHU
April 4, Liz Porteus, Speak and Voice
May 2, Jodi Ramsey, Hospice
June 6, Bailey Vernon, JHU Educator
July 11, Becky Dunlap, JHU RN, BSN
August 1, Meritus Pharmacist
Sept. 5, Dr. Samina Anwar, Neurologist
October 3, Bill Bugg, Author
Nov. 7, Steven Ryan, Physical Therapy
December 5, Break Out Sessions

Educational Activities

Winchester Parkinson's Support Group
February 12, 2013 – Art Guyer will be the guest speaker presenting "Caring for the Caregiver." Call 304-285-0496.

April 19, 2013 – Dr. Linda Sigmund will be their guest speaker. Call 304-285-0496.

Berkeley Co. Parkinson Support Group
February 16, 2013, 9:30 AM, Valentine's Breakfast Buffet. Reservations are closed.

PFNCA Annual Symposium
February 23, 2013. All day Parkinson's Symposium in Bethesda, MD.
Call 703-734-1017 for more information.

Caregivers' Breakfast

Monday, February 18, 2013, 8:30 am at the Railroad Junction Family Restaurant.
Call Art Guyer for information.

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Think Picnic!

Please let us know of any events you would like to see publicized.

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please email: aquyer42@myactv.net

Or call him at: 240-625-2722

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Caregiver's Breakfast.

Last month, Dave DeHaven, Ecile Shaw, Shirley Smith, Barbara Harrell, Mike Saterbak and Art Guyer enjoyed the Caregivers' Breakfast together. Yes! A total of 6 caregivers came out in the cold.

This month, caregivers will meet for breakfast on Monday, February 18th, at the Railroad Junction Family Restaurant in Hagerstown, at 8:30 AM.

You are encouraged to participate in this if at all possible. Caregivers should call Art at least 24 hours in advance, if you plan to attend or have questions



Birthdays

So we can celebrate your birthday at our meetings, we're collecting birthdates (just day and month).

To participate, sign up at the next meeting or contact Art who is keeping a master schedule for the group.

February Birthdays:

Doris Fearnow
Jamie Fleming
Jay Stouffer

Senior Resources

For good senior resource information, look for the *Senior Compass* at your local grocery stores and on line at:

www.seniorcompassresourceguide.com

Directions to the Western Sizzlin Steakhouse:

The Western Sizzlin Steakhouse is located just off Halfway Boulevard on York Road, about "halfway" between Valley Mall and Virginia Avenue. The street address is:

17567 York Road
Hagerstown, MD

From I-81, take Exit 5A, travel east 1.1 miles on Halfway Boulevard; at the second traffic light, turn right on York Road and take an immediate left.

Coming from east of Hagerstown (travelling west) on I-70, take Exit 28, travel west 1.7 miles on Halfway Boulevard; at the third traffic light, turn left on York Road and take an immediate left.

Coming from west of Hagerstown (travelling east) on I-70, take Exit 28, turn left on Downsville Pike, turn left at first traffic light, travel west 1.6 miles on Halfway Boulevard; at the second traffic light, turn left on York Road and take an immediate left.

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.

Upcoming Events (Cont. from Page 1)

Johns Hopkins Educational Seminars:

Parkinson's Disease 101: For newly diagnosed Parkinson's patients and family. March 11, June 10, September 23
5:00 PM – 8:30 PM

Parkinson's Disease 201: For patients diagnosed for at least 5 years, and family. April 22, October 28
5:00 PM – 8:30 PM

Deep Brain Stimulation: A session on the innovative technique to provide relief for people with Parkinson's Disease. April 8, November 11
6:00 PM – 7:30 PM

Achieving Excellence in Parkinson's Care: Presented with NPF at the Sheraton Baltimore North Hotel, Towson, MD. Saturday, May 18. 9:45 AM – 3:30 PM

For information on these JHU events, contact **Bailey Vernon** at 410-616-2811 or bvernon1@jhmi.edu.

Reminder!

We no longer mail hard copies of our newsletter to those on our mailing list with email addresses. We will make exceptions by individual request.

If you would like to receive this newsletter by email, send a note to Art asking to be put on our email list. You get the newsletter sooner by email! Plus you get extra, quick turn-around information.

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New Parkinson's Disease Treatments

Please consult your neurologist if you are interested in any of these new treatments.

Neupro Approved for Use in the United States

July 16, 2012 – UCB announced that Neupro® (Rotigotine Transdermal System) is available in U.S. pharmacies. The Neupro® “patch” was approved by the U.S Food and Drug Administration in April 2012 to treat the signs and symptoms of early and advanced stage idiopathic Parkinson's disease (PD) and moderate-to-severe primary Restless Legs Syndrome.

Neupro® improves motor function and activities of daily living in patients with PD and provides effective symptom relief for patients with Restless Legs Syndrome (RLS). Neupro® is a once-daily patch that provides continuous delivery of the dopamine agonist Rotigotine for 24 hours. Over 100,000 patients have been treated with Neupro® worldwide, and seven clinical trials for the approved indications have demonstrated efficacy, safety and tolerability.

The effectiveness of Rotigotine in the treatment of the signs and symptoms of idiopathic PD was established in five parallel groups, randomized, double-blind placebo-controlled trials conducted in the U.S. and abroad. Three early PD trials used the Unified Parkinson's Disease Rating Scale (UPDRS), a multi-item, four-part rating scale commonly used in PD trials. The trials showed Rotigotine was effective in helping to improve movement and function, versus placebo, in patients with early PD. Two trials of Rotigotine in patients with advanced PD examined change from baseline in “off” time, periods when the effectiveness of medication wears off and PD symptoms return. Statistically significant reductions in off-times were observed in advanced PD patients receiving Rotigotine compared with those who received placebo.

In clinical trials, the most common adverse reactions (about 5% greater than placebo) for the highest recommended doses of Neupro® for treatment of PD were nausea, vomiting, somnolence, application site reactions, dizziness, anorexia, hyperhidrosis, insomnia, peripheral edema, and dyskinesia.

IPXo66 (Rytary): A Possible New Treatment for Parkinson's Disease

Rytary is a possible new form of medicine for the treatment of PD made by IMPAX Labs. Like the already approved medicine, it is a pill containing both levodopa and carbidopa and is taken by mouth. It is different because it's made to release the medicines slowly over time instead of all at once. This may allow the patient to get the benefits of levodopa and carbidopa steadily over a longer period of time. This also means that people using Rytary to treat their PD symptoms would have to take fewer pills each day.

Rytary is still being studied, but so far the medicine looks like a promising treatment. In one clinical trial, people who took it had fewer PD symptoms than those who took the original levodopa and carbidopa pill. The study also found it is just as safe as the original pill. The FDA is still reviewing the clinical trials (at this writing) to decide if it is safe to use and does what it's supposed to do. Rytary could be approved by the FDA as early as the end of January 2013.

Duodopa: A Levodopa/Carbidopa Intestinal Gel

Duodopa is a gel made up of levodopa and carbidopa that goes directly into your intestines. People using Duodopa carry a small, portable (easily carried) pump that is attached to their body near their stomach for the entire day, while they are awake. Because the pump sends the medicine directly into the body, Duodopa can start to work faster and may help keep you symptom free for a longer period of time compared to other medicines taken by mouth.

Duodopa may be a good option for patients that still get symptoms of PD even while taking other relevant medicines. Treatment with Duodopa may allow patients to take fewer pills each day and may avoid the need for other surgeries to treat symptoms. On the other hand, Duodopa is not for everyone. The pump can only be removed at night, while the patient sleeps. They must also be able to take good care of their pump and agree to use it exactly as they are taught.

Duodopa was approved for use in Europe in 2004, but is still being reviewed by the FDA in the US.

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Legal Issues Behind Caregiving

Establishing a precedent when it comes to the care of a loved one is essential, especially with the legal aspects of finances and health care. Here are some points to consider when taking control over the legal responsibilities for your relative in need of care.

Tips to Remember when Dealing with Legal Issues:

- Find a lawyer who can help you establish a will or estate plan for your relative. A lawyer can also provide strong advice on other key developments in the life of your loved one.
- Discuss with your relative important financial aspects such as the location of documents, gaining access to their banking accounts, and stepping in to take over any financial responsibilities they may have.
- Look into the possibility of becoming the power of attorney for your loved one if they become incapable of caring for themselves. Often a durable power of attorney can provide better coverage instead of a simple one.
- A living will can provide an end of life decision for your loved one should they become terminally ill. This pivotal paper can tell a doctor just how much or how little care the person wishes to receive.
- Talk with other family members about the intentions of your relative and ask their advice should you feel unsure about any matter.
- Have your attorney distribute the proper documents to the doctors, banks, and health care providers of your relative.
- Understand what your loved one's insurance plan calls for in the event of hospitalization or hospice care.
- Be upfront with your relative about your feelings behind the decisions you make, and allow for them to offer their advice should they be of sound mind.
- Find out what financial protection is offered for your loved one when it comes to their Social Security and pension benefits.

Contact local agencies that deal with legal protection of the elderly and see what services they can provide.

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Phone: 240-625-2722
E-mail: aguyer42@myactv.net