

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

May 2013

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

Volume 3, Issue 05

[Visit us on Facebook](#)

This Month's Meeting

We had 41 attendees at our April meeting, including 3 new individuals. Thank you all for your financial and moral support, and for your participation in our first "break out" session this year. **Anita Masters** won the \$10 gift certificate door prize provided by the **Guyer** and **DeHaven** families.

It was good to see **Peg Hayzlett** back at our meeting, thanks for your help, Peg. Our thanks also go to **Ecile Shaw** for asking the blessing.

Dance for PD

We are bringing an exercise program to you called "Dance for PD" from the Bowen McCauley Dance organization. See Page 6 for information about this free and fun program.

April is Parkinson's Disease Awareness Month

Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment or the smallest act of caring. Leo Bascaglia

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, May 2, 2013, 11:45 AM.

Our Speaker in May will be

Jodi Ramsey

Community Relations Specialist
Hospice of Washington County

Information Requested at our Break
Out Sessions (Movement Specialists
and MOLST): See Page 3

How Good Are Generic Drugs? See
Page 4 - 6

Dance for PD Demonstration Class:
See Page 6

Upcoming Events

Future Meetings

May 2, Jodi Ramsey, Hospice
June 6, Bailey Vernon, JHU Educator
July 11, Becky Dunlop, 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 and Other Activities

Winchester Parkinson's Support Group:

April 19, 2013 - Dr. Linda Sigmund will be their guest speaker. Call 304-258-0496

Caregivers' Breakfast:

Monday, April 22, 2013, 8:30 AM at the Railroad Junction Family Restaurant. Call Art Guyer for information.

Dance for PD Demonstration Class:

April 26, 2013 at St. Mark's (See Page 6)

Continued on Page 2. Please let us know of any events you would like to see publicized.



This publication supports:

The Hagerstown Parkinson's Support Group

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22215 Troy Lane
Hagerstown, MD 21742

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!

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

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please email: aguyer42@myactv.net

Or call him at: 240-625-2722

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Caregiver's Breakfast.

In March, Dave DeHaven, Ecile Shaw, Peg Hayzlett, Barbara Harrell, and Art Guyer enjoyed the Caregivers' Breakfast together.

This month, caregivers will meet for breakfast on Monday, April 22nd, at the Railroad Junction Family Restaurant in Hagerstown, at 8:30 AM. Hopefully, we will be meeting in the private room at the restaurant.

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



Homestyle Cooking
(240)-625-9022
808 Noland Drive
Hagerstown, Md
21740

Hours:
Monday-Saturday
6:00 am-8:00 pm
Sunday 7:00 am-3:00 pm

www.railroadjunctionfamilyrestaurant.com

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.

April Birthdays: Gracie Churchman in Texas, Peg Hayzlett, Betty Martin, and Frank McConnell.



Passing Member



Please remember the family and friends of Marvin Meyers in your prayers and thoughts. He passed away on April 3. Local papers have his obituary available.

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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.



Thoughts for the Caregiver!

Patients sometime choose to shut down. They want to stay in bed, do not want to eat, do not even want to breathe.

They want you to do everything for them.

Take them out for coffee, lunch, ice cream, a drive, or just sightseeing.

If you need a short respite, find someone who is willing to help. You may be surprised how many people will help, how it can improve the patient's outlook, and how much you will enjoy the break.

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)

Totem Pole Playhouse Event:

Totem Pole Playhouse, "A Closer Walk with Patsy Cline," Wednesday, June 19th, at 2:30 PM, call 888-805-7056 to check for available tickets.

Summer Picnic:

Thursday, June 20, 2013, at 12 PM in Pavilion #4 in the Martin L Snook Memorial Park, Hagerstown, MD. Fried Chicken, Covered Dish, Dessert and Bingo. More Information to come!

Johns Hopkins Educational Seminars:

Parkinson's Disease 101: For newly diagnosed Parkinson's patients and family. 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. 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 more information on these JHU events, contact **Bailey Vernon** at 410-616-2811 or bvernon1@jhmi.edu.

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Movement Disorder Specialists

During our breakout sessions at our April meeting, a number of members asked for contact information for the movement disorder specialists and centers in the Hagerstown area. The following is compiled from the centers' websites:

Johns Hopkins University Medicine

The Parkinson's Disease and Movement Disorders Center

Anderson, William Stanley, MD PhD (410-966-6406)
Dawson, Ted Murray, MD (410-955-9441)
Dorsey, Earl Ray, MD (443-287-0516)
Lenz, Frederick A, MD (410-955-6406)

Mari, Zoltan, MD (410-502-0133)
Ricaurte, George A, MD (410-550-7095)
Rosenthal, Liana Isa Shapiro, MD (410-616-2824)
Dunlop, Becky (Nurse Coordinator) (410-955-8795)

www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/movement_disorders/

University of Maryland Medical Center

The Maryland Parkinson's Disease and Movement Disorders Center

Karen E. Anderson, M.D., Neuropsychiatrist (410-328-5660)
Melissa J. Armstrong, M.D., Assistant Professor of Neurology (410-328-5858)
Paul S. Fishman, M.D., Ph.D., Chief of Neurology, Maryland VAHCS (410-328-5858)

Stephen G. Reich, M.D., Co-Director (410-328-5858)
Lisa M. Shulman, M.D., Co-Director (410-328-5858)
Sharon K. Powell, R.N., M.P.H., Nurse Educator (410-328-7797)
Howard M. Eisenberg, M.D., Department of Neurosurgery (410-328-3514)

www.umm.edu/parkinsons/

Parkinsons & Movement Disorders Center of Maryland (443-755-0030)

Stephen Grill, M.D., Ph.D.
Joseph Savitt, M.D., Ph.D.
Shawn Smyth, M.D.

8180 Lark Brown Road, #101
Elkridge, MD 21075

www.pdmdcenter.com/index_frame.html

For those with internet access this link has a very good article on choosing a Parkinson's Specialist:

<http://www.care4dystonia.org/newsletter/StepstoFindingaMovementDisorderSpecialist.pdf>

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Medical Orders for Life-Sustaining Treatment (MOLST)

MOLST is a portable and enduring form for orders about cardiopulmonary resuscitation and other life-sustaining treatments. This form makes your treatment wishes known to health care professionals. This form does not expire and it goes where you go – to the hospital, rehab, assisted living, and back home.

For more information attend the Hospice of Washington County free community presentation on April 16, from 5:30 – 7:00 PM. Call 301-791-6360 for reservations. Forms and additional information are available at: <http://marylandmolst.org/>.

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How Good Are Generic Drugs?

by BERKELEY WELLNESS | FEBRUARY 26, 2013

In the last few years, many blockbuster prescription medications—including some leading statins, anti-depressants, and drugs for hypertension, reflux disease and osteoporosis—have become available as generics, and more brands will soon join the list. About three-quarters of prescriptions in the U.S. are now for generic drugs. This has trimmed hundreds of billions of dollars from the nation's rising health-care costs and, by allowing more people to afford the medication they need, has undoubtedly saved countless lives.

The Food and Drug Administration (FDA), insurers and virtually all medical groups insist generics are as effective and safe as the original products. Still, some people believe cheaper drugs can't be as good as brand names and fear switching to generic is risky.

How equivalent are generics?

The FDA requires generics to measure up to the originals in terms of strength, quality, purity and safety. Generics must deliver to the body the same amount of active ingredient, at very close to the same rate, as their brand-name counterparts—this is called bioequivalence. (Some generics are made by the same manufacturers that make the branded drugs and are then sold to the generics companies, in which case the drugs are truly identical.) The FDA requires manufacturers to do bioequivalence testing of generics, though not necessarily of all formulations; it rarely does the testing itself. Complicating matters is the fact that generics for a specific drug are typically made by several companies.

Even though brand name and generic drugs have the same active ingredient, the drugs can differ in shape, color and inactive ingredients, such as preservatives and fillers. A generic tablet may be harder or softer than the original, which could affect how quickly it dissolves and is absorbed. And a generic of a time-release drug may employ a different mechanism to gradually release the active ingredient.

For these and other reasons, generics may not be the exact bioequivalent of the originals. The FDA does allow some leeway for generics (as well as for differences among brand-name drugs). Its reviews of thousands of studies have found that the absorption of generics differs from the brand names by only 3 to 4 percent, on average, comparable to differences among batches of many brand-name drugs. Such a small difference won't matter for most drugs, but for some it may reduce effectiveness and/or safety. Moreover, that "average" difference disguises a wider range of variability in bioequivalence.

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When Drugs Go Global

Concerns about generics grew in November 2012 when Ranbaxy Pharmaceuticals, a leading generics manufacturer in India, had to halt production of its version of the cholesterol-lowering drug atorvastatin (brand name Lipitor) because tiny particles of glass were found in some lots. This was just the latest in a series of manufacturing problems by Ranbaxy.

It's estimated that 80 percent of all active ingredients and 40 percent of finished drugs sold in the U.S. are now imported. The biggest drug companies are still located in North America, Europe and Japan, but India and China are striving to catch up. They have a big advantage to offer—lower prices.

Drugs made in the U.S. are regulated according to strict standards, and manufacturing facilities undergo periodic FDA inspections; Canada and the European Union have their own standards. But this is not generally true in other countries. The FDA does inspect foreign plants that make drugs exported to the U.S., but they have had limited resources to do so. The disparity has been greatest for generic drugs: the FDA inspects foreign manufacturers once every 10 years, on average, compared to every two years for domestic plants.

A law passed by Congress in 2012 requires the generic drug industry to pay fees so that the FDA will be better able to ensure the safety and quality of generics. Among its many benefits, the law will enable the FDA to inspect foreign generic manufacturing facilities every two years. It will take time, however, for the FDA to catch up.

"Imported" is not necessarily a dirty word, for brand-name or generic medication. We just need better quality control.

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Red flags for generics

The clearest example of a faulty generic has been the anti-depressant bupropion XL, which is a stand-in for Wellbutrin XL (XL indicates extended-release). Since generic bupropion XL came on the market in 2006, many people reported problems when they switched to the generic version of the once-a-day 300-milligram tablet. Some started feeling suicidal or had panic attacks, bouts of crying and other signs that the drug wasn't working well. There were reports of new side effects, too, including insomnia, headaches and nausea.

The FDA initially downplayed these complaints; even after a 2007 analysis found one company's bupropion XL 300 released high doses of its active ingredient in just a few hours (the original drug was designed to slowly release smaller doses over the course of the day). Recently, after conducting its own study, the FDA acknowledged this problem and told the company (Teva Pharmaceuticals) to stop selling the drug. The FDA has asked other makers of bupropion XL 300 to do bioequivalence testing and is now looking more carefully at other extended-release generics as well.

The Psychology of Price

You're just as likely to experience new drug side effects when switching from one brand to another brand as you are when switching from a brand to a generic—in theory, at least. One complication is that because generics are cheaper, some people think they aren't as good. And, studies have shown, this worry and doubt when switching to a generic can actually increase the likelihood of poorer results and adverse effects. This is called the nocebo effect, which occurs when negative expectations influence the effect of a drug or other treatment. (With the placebo effect, positive expectations and belief help improve the effectiveness of a treatment.)

It's important to know what the potential side effects of any drug are, of course. But if you're prone to worrying, watch out for your negative expectations when you switch to a generic. And remember, when it comes to drugs, don't let the price fool you. Some of the best drugs we have—aspirin and penicillin, for instance—are cheap and generic.

Another potential red flag: During the last decade, patients, hospitals and researchers reported reduced efficacy and increased side effects with certain generic anti-seizure medications for epilepsy, notably levetiracetam (brand name Keppra).

Generic safety tips

These reported problems should not make you doubt generics. The vast majority are safe and effective. Some small variations among drugs, generic or brand name, are inevitable. Insurers and government health plans very strongly encourage or require the use of generics, and for good reason. Even if your prescription form indicates a brand name, your pharmacist is likely to give you the generic version if one is available—some states even mandate this—unless your doctor specifies "brand only," "do not substitute" or "dispense as written." Some states also allow you to request that the pharmacist not substitute the generic. The brand-name drug will cost you more, however.

To be on the safe side, keep the following in mind:

- ✓ If you switch from a medication (brand-name or generic) to a version by another manufacturer, be aware of any changes in your condition or side effects you may experience.
- ✓ Watch out, in particular, if you're taking an extended-release drug for a condition that requires a constant blood level of the active ingredient and you switch to a version from another company. Extended release drugs are tricky to make. The delivery system can vary from product to product, and some may release the ingredient too quickly or too slowly.
- ✓ In addition, watch out for changes if you switch to a generic of a drug that has a narrow therapeutic window (meaning you can get in trouble if your blood level is a little too low or high). That includes thyroid medications, anti-seizure drugs and the blood thinner warfarin (brand name Coumadin). Ask your health care provider or pharmacist if your medication falls into this category.

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- ✓ Pharmacies often get the same generic drug from different manufacturers, depending on price and availability. So if you're taking one that's working well, you may want to check the bottle for the name of the maker and tell your pharmacist you want to stick with that one. If it is no longer available there, you may have to go to a different pharmacy.
- ✓ If you have problems or side effects with any drug—generic or brand-name— talk to your health care provider about possible alternatives. If it's a generic, you should also alert your pharmacist, since he/she may want to get the drug from a different maker. Your health care provider and/or pharmacist should, if appropriate, file a MedWatch report to the FDA. You can also file a report yourself by mail or fax; call MedWatch at 800-FDA-1088 for the form. Or download it at www.fda.gov/medwatch/how.htm.

Dance for PD

We are having a “Dance for PD” demonstration class on April 26, 2013, from 3:00 – 4:00 PM, at St. Mark's Episcopal Church, 18313 Lappans Road, Boonsboro, MD 21713. Directions are included below. Peg Hayzlett has volunteered to head up this effort and has arranged for this time and location. If the demonstration is successful, we will arrange for the full class schedule. If you have any questions or if you have not signed up at one of our meetings, call Peg at 301-791-0836.

In partnership with the **Parkinson Foundation of the National Capital Area**, Bowen McCauley Dance is the only dance company in the Metropolitan-DC area to provide Dance for PD -- free weekly dance classes for people with Parkinson's Disease and their care-partners. Besides the health benefits, dance takes the mind and spirit away from the thoughts of disease, disability and social isolation.

In a study of patients with Parkinson Disease, researchers from Washington University School of Medicine in St. Louis have found that those patients who participated in dance classes showed significant improvement in balance and mobility over those who participated in non-dance exercise programs.



Directions:

St. Mark's is located south of Hagerstown, MD, at: 18313 Lappans Road, Boonsboro, MD 21713.

You can reach the Church from I-70 by taking exit 29 and turning south toward Sharpsburg on Sharpsburg Pike (Rt. 65). Drive 4 miles and turn left at the light at Lappans Road (Rt.68). You will see the Church sign ahead on the right.

Prepare to turn right at the Parish House and continue towards the back of the campus for a large parking lot.

For more information and videos go to this link: <http://www.bmdc.org/outreach/dance-for-pd>