

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

January 2013

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

Volume 3, Issue 01

December Meeting Highlights

Our first winter meeting held at a new location, the *Western Sizzlin Steakhouse*, was declared a complete success. We had 26 members attending, including two new individuals, one of which travelled over an hour to join us. I want to thank both of these people who will undoubtedly contribute as well as get information.

Dick Naugle presented a Christmas poem, asked the blessing, and even told a "thinking man's" joke about Santa's little known reindeer – "Olive". That is as in "All of" the other rein-deer! Everyone enjoyed the wide selection from the buffet and regular menu, as well as conversation around the tables.

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

Please keep Huck Hayzlett (the fisherman) in your thoughts; he soon will be entering a nursing home. More info next month.

PLEASE NOTE THIS CHANGE

The January 3rd meeting will begin at Noon and we will start with our speaker followed by lunch around 1:00 PM. This appears to be better for speakers and we will not have to rush through lunch and the speaker will not have to wait. Please come at least 15 minutes early so the speaker can begin promptly at 12 Noon. We will probably use this format for all of our meetings in the future.

The Hagerstown Parkinson's Support Group Contact

Group Facilitator, Art Guyer:
Phone: 240-625-2722
E-mail: aguyer42@myactv.net

January 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

Directions are on page 2 and on our website.

Thursday, January 3, 2013, 12 Noon.
Please come 15 minutes early.

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

Our Speaker will be
Dr. Paul Dash, Neurologist
Johns Hopkins Medical

Why Do You Need a
Movement Disease Specialist!
See Page 3

Seven Essential Do's and Don'ts for
People Who Care for Caregivers
See Page 4

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

January 3, Dr. Paul Dash, Neurologist
February 7, Kathy Fisher, Senior Center
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, Break Out Sessions
Sept. 5, Dr. Samina Anwar, Neurologist
October 3, Bill Bugg, Author
Nov. 7, Steven Ryan, Physical Therapy
December 5, TBD

Educational Activities

Winchester Parkinson's Support Group
February 12, 2013 – Art Guyer will be the guest speaker presenting Caring for the Caregiver.

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

Caregivers' Breakfast

Tuesday, December 18, 2012, 8:30 am
Call Art Guyer for Information.

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

Directions to the Western Sizzlin Steakhouse Restaurant are on Page 2.

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.

Last month, Dave DeHaven, Peg Hayzlett, and Art Guyer enjoyed the Caregivers' Breakfast together.

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

This restaurant has a good breakfast, lots of coffee, and we provide conversation and fellowship. 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 this breakfast. If transportation is a problem, let Art know when you call.

Birthdays

We're collecting birthdates (not years, just day and month) so we can celebrate a little at each meeting for those with birthdays that month.

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



December Birthdays:

Linda Embly, Clyde Fearnow, and David Fleming celebrate birthdays this month.

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
(301-791-7560):

From Interstate 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.

From Westbound Interstate 70, take Exit 2B, travel West 1.7 miles on Halfway Boulevard; at the third traffic light, turn left on York Road and take an immediate left.

From Eastbound on Interstate 70, take Exit 2B, 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.



Reminder!

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

If you are not receiving this newsletter by email, send an email 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.

MARYLAND ASSOCIATION FOR PARKINSON'S SUPPORT

This is a grass roots effort to improve the lives of people impacted by Parkinson's disease in the region. The purpose of this effort is to create a local organization that will provide resources, information, and support to the people with Parkinson's disease (in Maryland). Your ideas and input are important as a coordinated resource group is developed that will offer support, information, and resources for the regional Parkinson's community.

Research has shown an umbrella organization is one of the best ways to fund and manage non-medical activities and information for people with Parkinson's. The Parkinson Foundation of the National Capital Area (PFNCA) is a highly successful non-profit organization in Washington D.C. dedicated to Parkinson's disease education and patient services, and serves as an excellent model for Baltimore (Maryland).

If you would like to participate in this developmental effort or have any suggestions or comments on this effort, please contact Bailey Vernon, *Johns Hopkins*, by phone at 410-616-2811 or email her at bvernon1@jhmi.edu.

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WHY DO YOU NEED A MOVEMENT DISORDERS SPECIALIST?

Art Guyer, Facilitator for the Hagerstown Parkinson's Support Group, from Internet Research

Many people feel their family doctor can provide good care right in the neighborhood. They value the convenience of a local doctor who is devoted 100% to clinical care and want to receive standard care.

Others feel that going to a neurologist who is a movement disorder specialist is important because these academic physicians are astute, experienced, dedicated and "on the cutting edge" of new treatments. Specialists are aware of all current therapies, their benefits, limitations and side effects. These specialists coordinate the best course of treatment for each person.

A movement disorder specialist is a doctor, a neurologist in fact, trained specifically to treat movement disorders. Parkinson's disease is a movement disorder – a neurological condition that affects movement. Other movement disorders include dystonia, Tourette's syndrome and Huntington's disease. Movement disorder specialists must complete their residency training in neurology and then complete additional training (a fellowship) in movement disorders.

These are the most qualified doctors to treat Parkinson's disease because of their in-depth knowledge of the disease, its symptoms, medications and current research (including relevant clinical trials).

The Parkinson's Disease Foundation recommends that each person with Parkinson's see a movement disorder specialist. There may not be a movement disorder specialist in your area but traveling an hour or more 2 to 4 times a year should be well worth the difference in the level of care you receive. If necessary, seeing a good local neurologist in consultation with the specialist is also a workable arrangement.

Finding the right doctor can drastically improve how supported and educated you feel, and how well your Parkinson's symptoms are managed. If you or a loved one has Parkinson's, you may already realize how crucial finding the right doctor is to feeling supported and healthy.

If you have Parkinson's, you should see a neurologist who specializes in movement disorders and one who is up-to-date on research and approaches to therapy. If you need assistance in finding a specialist, the Parkinson's Disease Foundation can be of help. Also, your primary care physician should be able to make a referral, as well as others living with Parkinson's disease. Your insurance provider should also be able to provide a list of neurologists and movement disorder specialists.

Another way to get information on specialists is to join Parkinson's Disease Support Groups. These groups can be a good source of social and emotional support and many Parkinson's support groups focus on helping their members learn how to live well with this chronic illness. PD support groups often feature guest speakers on a specific educational topic each month.

Many movement disorder specialists work at a basic science level to better understand these disorders. They may be working with genetic material or cell lines in glass dishes to understand the step by step process that leads to people developing the disease they are studying. They may be conducting clinical research studies to further our knowledge of a disorder, family studies searching for a disease-causing gene or experimental drug studies to further our knowledge of specific treatments. They may be examining brain tissue from brain donor patients to better understand the brain cell abnormality that causes the disease.

But the first and most important role of these specialists is to provide the best care to their patients and caregivers. They take a long meticulous health history and ask you to complete a written history of your health. They observe the problems you are having and put the difficulties into perspective. As they examine you, they will begin to build "a picture" of the characteristics of the movement disorder you have. They may collaborate with colleagues to discuss the correct diagnosis and the course of treatment if there are unusual clinical features. These clinicians will spend a major part of every visit teaching you and helping you understand your movement disorder. Together they will decide with you and your family the best possible therapy.

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Seven Essential Do's and Don'ts for *People Who Care for Caregivers*

By Lisa Lopez; Edited by Art Guyer

As a caregiver, one will experience everything from anger to guilt, from optimism to despair. Friends are extremely important to a caregiver. Often friends just get it. They don't need to be told what questions to ask, when to ask them or when to leave one alone. However, close family members often have to be reminded how to react to the very fragile and stressed side of a caregiver. Here are some tips to the wonderful people who care for caregivers.

The Do's and Don'ts:

1. DO LISTEN - It may seem like a simple concept; but for some people, the idea of listening can be a hard job. A word of advice to those caring for caregivers: when your loved one is stressed or wants to talk about their day, just listen. Stop what you're doing and give them your full attention. You don't even have to speak. A hug every once in a while wouldn't hurt either!

2. DON'T OFFER UNSOLICITED ADVICE – This is another toughie for the folks who love and care about caregivers. It's hard because you hate to see your loved one in pain. Each time the caregiver in your life comes to you with another problem or unpleasant situation, you try to fix it. It's very common and well-intentioned. If you're caring for a caregiver, stop before you offer advice. Remember, chances are the caregiver in your life has never had a dress rehearsal for this role. They're doing the best they can and will ask you if they need your advice.

3. DO GIVE THEM THEIR SPACE – Space, the "vital" frontier. When you're given the enormous responsibility of caring for someone else, you feel like you're in a fishbowl. Family members, doctors, bill collectors, you name it, are constantly in need of something. Occasionally, one needs time and space to recharge the batteries. Whether it's a nap, time with friends, a massage or a weekend away, caregivers need to take the time to care about themselves. When the caregiver in your life says they need a break, don't hesitate – pack a suitcase, make reservations for a weekend away, or just follow their lead. Time and space away from the duties and responsibilities of caregiving is essential to avoiding burnout.

4. DON'T GIVE THEM A GUILT TRIP – People caring for caregivers may have a difficult time understanding the changes needed in one's life when one becomes a caregiver. They may feel abandoned because suddenly the caregiver is devoting a major portion of their time to the patient. This includes direct care, evaluating care services, meeting with lawyers, talking to social workers, and piles and piles of paperwork. The person caring for the caregiver may get in the habit of making one feel guilty about the time spent attending to the patient's needs. This will only make a highly stressful situation worse and it will cause resentment.

5. DO HAVE EMPATHY – You never really understand a person until you look at his point of view. If your caregiver's family member doesn't already live with you, make a point to accompany them to visit their loved one from time to time. This will give you a glimpse into their world and what they are going through.

6. DON'T JUDGE – No matter what your loved one's relationship is to the person they're caring for, remember it's their choice to be the caregiver. No matter the circumstances, leave the judgment out of it, accept your loved one's choice and support them in any decision they make.

7. DO LAUGH – Laughter can be the main thing that gets one through great difficulties. Loosen up and follow your loved ones' lead. If they're laughing, join in. It's contagious and that's a sickness everyone can afford to catch.

Lisa Lopez is a Grants Research Manager at a nonprofit organization in Greensboro, NC. Lisa and her family have been caring for her 68-year-old father for more than a year. She is an avid writer of short stories, plays, screenplays and essays. She has a Masters of Public Affairs from the University of North Carolina at Greensboro. She lives with her husband, two dogs and five cats.