

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

SEPTEMBER 2015

Dr. Mark Lewine, Editor

SEPTEMBER MEETING

Wednesday, September 2, 2015 – 2:00 p.m. till 4 p.m.

We welcome from The Hospice of the Western Reserve, LaBena Fleming, Provider Relations Manager, who will speak on **Advanced Care Planning – Courage in Conversation**. Learn the importance of making decisions regarding future medical care and discussing family/loved ones. Take home an advanced care planning guidebook with Ohio advanced directives, including the Living Will and the power of attorney health care form.

Cleveland Heights Recreation Center
One Monticello Boulevard, Cleveland Heights, OH

(Last names A through M, please bring light refreshments)

From David Brandt

I hope everyone is enjoying the summer. By the time you are reading this, my family will be back from our trip to the San Francisco area including stops at Napa Valley, Lake Tahoe, Yosemite, and Monterey. We have been fortunate to take a family vacation every year even though our kids are getting older (the oldest is almost 29). We know having the kids join us won't last forever but we cherish it for as long as it happens. Hopefully you are able to spend time with family or friends sometime this year!

InMotion is holding an event on Friday, August 28 from 7:30 p.m. to 9:30 p.m. at their location in Warrensville Hts. featuring Dave Iverson and a screening of his film *Capturing Grace*. Here is the description – It seems like two separate realms. One is occupied by acclaimed dancers from Brooklyn's world renowned Mark Morris Dance Group, the other by people with Parkinson's disease. *Capturing Grace* is about what happens when those two worlds intersect.

Dave Iverson's remarkable documentary reveals the hopes, fears, and triumphs of this newly forged community as they work together to create a unique, life-changing performance. There will be a discussion and reception following the film. To learn more or to make reservations, please call them at 216-342-4417.

PEP October Meeting October 7, 2015

Tom Strong, Medical Lecturer with 30 years experience as an educator, will talk on
**Vitamins and Supplements and
Understanding Your Medications**

TRIBUTES

Paul and Jane Gaydos

In memory of Deacon Jim Duffy
Mary Ann Duffy

TO REACH US AT PEP

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Facebook – Parkinson Education Program of Greater Cleveland

DISCLAIMER: The material contained in this newsletter is intended to inform. PEP makes no recommendations or endorsements in the care and treatment of Parkinson's disease. Always consult your own physician before making any changes.

Top Questions to Ask Your Doctor

(Excerpt from www.parkinson.org)

Get answers to these questions so you can take better care of yourself.

Q: Why is this medication being prescribed/What symptoms signal a problem, and how should I respond?

You want to make sure you have complete understanding of your medication regimen, including potential drug interactions and side effects.

Q: How will you monitor my Parkinson's treatment/Who will coordinate my care?

Find out who your main contact is, when you should return for your next visit, and how frequently your medication schedule will be evaluated and adjusted.

Q: What other professionals do you recommend I see?

Ask for a referral to a physical therapist, speech-language pathologist, occupational therapist and social worker. Ideally, you'll be assessed by these providers at least once.

Q: What types of exercise and wellness activities are most suitable for me?

It's a good idea to find out about local exercise classes and support groups geared toward people with movement disorders.

Q: What happens if I begin to feel depressed?

People with chronic health problems are most at risk for depression. If you think you may be depressed, ask your doctor to screen you.

Q: Can you recommend a dermatologist?

People with Parkinson's have a higher risk of developing melanoma, a potentially lethal skin cancer, and should be screened once a year.

Q: What are the best ways to prevent or manage constipation?

Ask your doctor about strategies to relieve symptoms such as proper dietary fiber intake or changes in medication.

Q: What treatment options are available for sleep disturbances?

More than three-fourths of people with Parkinson's report sleep-related symptoms.

Q: What are the latest developments in Parkinson's treatment/Is there a clinical trial **appropriate for me**?

Clinical trials are research studies that give patients access to promising new medical treatments that aren't available yet to the public.

Q: What hospital should I go to in an emergency?

CARE-GIVERS CORNER

CREDO

Our Support Group involves people who serve as care-givers out of love; the hard and stressful work involved is rewarded by the kind of close and tender relationships that others only wish for.

- We will lighten our load as we find more ways to share the experiences of care-giving with each other in person and with our whole group, especially with those who can only read this newsletter.
- We will learn from one another and to also be comforted from knowing that we are not alone.
- We will open up with each other carefully with respect, but will be open in sharing the great stresses we experience.
- We will share some successful ways of coping as well as some of our 'not-so-good' choices, and most importantly, the deeply rewarding experiences that care-giving has given to us.

Early Stage Caregiving – Beginning your journey with Parkinson's

(Excerpt from <http://www.parkinson.org>)

Many families know for years that "something" is wrong. But the official diagnosis of idiopathic, typical Parkinson's disease can still come as a shock, often misclassified as denial. People often ask:

- How can the doctor know for sure?
- Shouldn't tests be run? (There are no definitive lab or imaging tests for Parkinson's disease.)
- Should we get a second opinion? (In many cases, yes! A neurologist who has completed a fellowship in movement disorders is most qualified to make the diagnosis.)

(cont'd on Page 3)

CARE-GIVERS CORNER *(cont'd)*

These are valid questions. As you begin your research into the disease and what it may mean for the person with Parkinson's disease, you will also have to figure out what it means for you.

How do I adapt to the diagnosis?

When your loved one was diagnosed with Parkinson's, it probably changed your life overnight. However, caregiver is a role and an identity that you grow into.

Parkinson's is a progressive disease. That can make it hard to define your role in your loved one's journey, as your involvement and responsibilities will change along the way. You must consider how to share the diagnosis with family, assess your work-life balance and prioritize your own needs.

Consult with an experienced caregiver

It can be helpful to you, the person with Parkinson's disease and your family to have a conversation with a seasoned caregiver. He or she has already gone through many situations you will likely face down the road and can share strategies for dealing with them. An experienced caregiver can also provide reassurance that this chronic health condition is highly "livable" and progresses slowly in most patients.

Build your Parkinson's disease knowledge base

As your loved one progresses through stages of Parkinson's, you will progress through stages of caring. Learn all you can about the disease early on so you can participate in health care discussions, make informed decisions and provide emotional and physical support now and as needed in the future. To start:

- Order NPF educational materials to familiarize yourself with Parkinson's. "What You and Your Family Should Know" and "Medications" are two good titles to start with. "Caring and Coping" is our book specifically for care partners.
- Explore whether there is a Parkinson's support group in your area to learn more about the condition from other people with Parkinson's disease and caregivers. Contact the NPF Helpline if you need a referral at 1-800-4PD-INFO (473-4636) or helpline@parkinson.org.

Begin the Parkinson's disease journey

Parkinson's impacts each person in a different way, so there is no one-size-fits-all approach to caregiving. Your journey is unique, but you share it with the person with Parkinson's disease:

- Discuss together how you will share the news with family and friends. If you have children still living at home, choose a level of information and an approach that are age-appropriate. How do you begin to explain Parkinson's disease? Read the NPF tip sheet "How to Talk with Your Family about Parkinson's."
- Be prepared for an onslaught of free advice. Friends and adult children are notorious for suggesting "miracle cures" from the latest article they just read online about Parkinson's disease. Be polite, but run all ideas past the neurologist. If they are persistent, share the NPF tip sheet for secondary caregivers, "What Not to Do."

At the same time, always remember to consider your own needs for wellness, self-care and support!

TRIBUTES

We need your donations to continue bringing you the *PEP* News and for other expenses. A special thanks to those who contribute at the monthly meetings. To send a donation, please make your checks payable to Parkinson Education Program and mail to – 17930 Birch Hill Drive; Chagrin Falls, OH 44023

PEP NEWS

Parkinson Education Program
of Greater Cleveland
17930 Birch Hill Drive
Chagrin Falls, OH 44023

FIRST CLASS MAIL

We try to keep our roster current. If you no longer wish to receive this bulletin or would like to receive it via email instead, notify Katherine.A.Kaminski@gmail.com or call 216-513-8990.

Nature Walks May Be Good for Your Brain, Study Finds

(Excerpt from www.michaeljfox.org)

Picture yourself taking a leisurely walk along a wooded path, sun peeking through the trees. Feel relaxed already? Several recent studies suggest that spending time outdoors has both mental and physical benefits. The latest one takes that research a step further – it used a brain scan to capture nature’s effect on how we think.

In the study, researchers asked 38 residents of an urban area to take a walk. Half strolled through a natural area, while the other half walked along a busy road.

Before and after the study, participants filled out a survey that aimed to capture their thinking patterns. In particular, the surveys measured participants’ tendency toward rumination. That style of often negative, inward-looking thinking is linked with a higher depression risk.

Participants also had their brains scanned before and after the walk.

The results? Questionnaires revealed that the participants who took a nature walk changed their thinking pattern. Brain scans matched those improved moods.

“This provides robust results for us that nature experience, even of a short duration, can decrease this pattern of thinking that is associated with the onset, in some cases, of mental illnesses like depression,” Gregory Bratman, the lead author of the study, told The Washington Post.

More research is needed to learn more about the link between nature walks and improved mental health. Exercise already provides a health boost, though, so there’s already a strong case for taking your walk through the park.