

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

OCTOBER 2015

Dr. Mark Lewine, Editor

OCTOBER MEETING

Wednesday, October 7, 2015 – 2:00 p.m. till 4 p.m.

Understanding Your Medications – Did you know we are more at risk for side effects as we age? Join us for this informative talk as noted medical lecturer and patient advocate Tom Strong discusses how drugs work, what causes side effects and how you can protect yourself as a consumer of medications.

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

(Last names N through Z, please bring light refreshments)

From David Brandt

- Pat and I along with many others went to see the film Capturing Grace at InMotion in late August which also featured a talk by David Leventhal, who was featured in the film as an acclaimed Mark Morris Dancer who helped a group of people with Parkinson's put on a unique life-changing performance. It was a wonderful film and my thought is to purchase a copy of it so that we can show it in one of our early 2016 monthly meetings for all to enjoy. I will let you know when I get it scheduled.
- I want to take this time to thank the Laretta K. Peters and Richard R. Peters Charitable Foundation for another very generous grant to PEP. Their significant contribution goes a long way to helping offset the annual costs of our monthly newsletter. Mr. Peters, himself a victim of Parkinson's Disease, intended to further public awareness and provide support for those struggling with the disease.
- One of our fellow PEP members, Ruth Ness, has generously offered to donate a blue fabric lift chair that has been rarely used. Please call her at 216-932-5579 if you are interested.
- Reminder to save the date – November 15, 2015 – for the Come Dance With Me Brunch with music by the Swing City Big Band at Laverhaven.

New Artificial Neuron Will Help Restore Neuronal Functions

(Excerpt from www.pcrm.org)

Neurological disorders are currently treated using traditional medications and electric stimulations. A group of scientists at Karolinska Institutet in Sweden has recently developed an organic electronic neuron made of conductive organic polymers. This artificial neuron is able to function like a real human neuron: It can sense changes of chemical signals and translate these signals into an electrical impulse that causes the release of a neurotransmitter (e.g., acetylcholine). The effects induced by the neurotransmitter's release can be further measured on human cells in vitro. This new neuronal model will help to bypass damaged nerve cells and restore neural function, possibly contributing to the treatment of neurological disorders.



PEP November Meeting November 4, 2015

At our November meeting we welcome Ben Rossi, Performance Coach at ATP Evolution Performance Training and Physical Wellness Director at InMotion

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.

Mid-Stage Caregiving – Preparing for Changes that are Likely to Occur Over Time

2ND IN A SERIES OF 3

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

Parkinson’s is a progressive disorder, and the rate of progression varies tremendously from one person to another. As a caregiver, try not to predict problems – instead, be prepared for changes that are likely to occur over time.

What should I expect?

While medications may significantly reduce symptoms in the first few years of the illness, physical abilities will decrease and Parkinson’s disease symptoms will increase as the years go by. People caring for someone at this stage of the disease may notice the following:

- **Inconsistent response to medications** – Appearance of “on/off” fluctuations in response to levodopa is common. Fatigue can also be an issue. This makes it hard to plan activities, as you cannot predict physical capabilities, and Tuesday may be different than Wednesday. Caregiver flexibility is important! Try these [tips](#) for scheduling in the face of fatigue.
- **Mood and cognition changes** – Changes to how the person feels, thinks and reasons may become more problematic than the motor symptoms of the disease (how the person moves), for both you and the person with Parkinson’s disease.
- **New safety considerations** – If symptoms begin to significantly affect mobility, memory or thinking skills, it may be time to consider if it is still safe for the person with Parkinson’s disease to perform tasks that he or she once did easily as part of the daily routine. For example, driving an automobile may become too risky, for your own family’s safety or that of others on the road. Giving up driving is an enormous loss of independence to many people and can create a new burden for the caregiver.
- **Physical symptoms that are better relieved with non-medication therapies** – Many people find that exercise groups and physical or occupational therapy help with motor symptoms of Parkinson’s disease. For communication problems, which occur partly as a result of soft voice (a common issue in people with Parkinson’s disease), refer to the NPF tip sheet “[Addressing Your Loved One’s Communication Challenges](#)”; you might also seek a referral for specialized speech therapy. Don’t discount the importance of exercise; findings from NPF’s *Parkinson’s Outcomes Project* have shown that people who begin regular exercise early in the disease experience a slower decline in quality of life.
- **Role conflicts** – People with Parkinson’s and primary caregivers rarely adjust to living with Parkinson’s disease at the same rate! You might need to adjust household and lifestyle responsibilities and habits. For example, should you start paying the bills? Is it time to hire someone to do the yard work? This can be a hard transition, and the very person you’re trying to help might resent these changes.
- **Early signs of caregiver fatigue:** After increasingly “taking the lead” in your relationship (with no end in sight), it is understandable if you regret that life is not turning out the way you expected or hoped. As the disease progresses and your role as caregiver evolves, you will have to come to terms with the disease again and again. Try these [tips for managing caregiver stress](#). (cont’d on pg. 3)

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.

CARE-GIVERS CORNER *(cont'd from pg. 2)*

Get outside help

No one person is ever able to meet all of an individual's needs, and as Parkinson's progresses this becomes more and more true. Begin adding outside resources to your caregiving early on. This makes adding other care sources easier as the disease progresses.

Start building your "Caregiving B Team"! These key friends and family members are the people who will be your back-up when you have other obligations or take a much-needed break, or who you call in an emergency. They can help you in small ways now and establish a relationship with the person with Parkinson's, making it easier for them to fill in for you in the future when the need becomes greater. Use this [worksheet](#) to help you add family, friends and volunteers to your caregiving.

If you are considering hiring a paid caregiver, visit [Outside Help](#) for information on where to look for help, questions to ask when hiring, how to train a paid caregiver and more.

Plan ahead

There are steps every adult should take, regardless of health status, to align your values, wishes and preferences with medical care you will receive. If you haven't done so already, make sure crucial planning documents such as a will, durable power of attorney and advanced directives are in place for both you and the person with Parkinson's. Visit [Putting Things in Place](#) for details on how to start the conversations and who can help.

Take care of yourself

Caregivers have an enormous, often underappreciated job. There are many things you can do to help make sure the role can continue to be – or return to being – a healthy, viable, even rewarding option for you. Here are just a few of those ideas:

- **Forgive** yourself for not being perfect.
- **Acknowledge** your right to feel emotionally off-balance.
- **Determine** your limits.
- **Build in regular breaks** from caregiving, and make them a priority.
- **Seek joy in your relationship** with the person with Parkinson's.
- **Last, but not least**, enlist the help of the person with Parkinson's to take care of you, as well. It takes a lot of Parkinson's symptoms to render someone unable to do a loving foot rub or neck massage!

Working Toward A Cure: Progress In 2015

(Excerpt from www.michaeljfox.org)

2015 has seen significant advances in Parkinson's care and research, including therapeutic advances to improve patients' lives, and our Foundation continues to target the most promising ideas in the pipeline.

Alongside our number one goal of speeding a cure for Parkinson's, our Foundation has always worked to highlight the critical need for improved symptomatic treatments for those living with Parkinson's today. Just last week the FDA approved a new deep brain stimulation device, giving patients and families a new option to address motor symptoms. *(cont'd on pg. 4)*

TRIBUTES

The Laretta K Peters and Richard R. Peters
Charitable Foundation

Lillian E. Joliat in honor of Claire Joliat

Maxine Jacqmin

Anonymous

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
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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.

Working Toward A Cure: Progress In 2015 *(cont'd from pg. 3)*

Our Foundation is currently funding research into next-generation DBS to improve and expand this treatment through sending electrical stimulation only when brain function requires, potentially extending battery life and decreasing side effects. The past year has seen great progress in the area of drug development as well, with two new formulations of levodopa receiving FDA approval early in 2015, and several Foundation-funded novel delivery strategies advancing in clinical trials.

We've also taken on new initiatives and fostered key collaborations. One of these is the debut of Fox Insight, an online research study and portal for data from wearable devices and smartphone apps. This virtual clinical trial brings patients and families greater access to digital opportunities in Parkinson's research and new options for conveniently tracking symptoms.

I invite you to learn more about others, which include awarding an inaugural prize in dystonia research and helping grow the global base of Parkinson's-trained specialists.

As always, our urgent work to explore drug targets for therapies to slow or stop Parkinson's progression continues at an ever-increasing pace.

It's been a busy six months here at MJFF, but we're eager to take on more. Our community's continued involvement in our mission helps us keep our momentum – so thank you. You help us get closer to making a difference in the lives of millions with improved treatments, and, ultimately, a cure for Parkinson's.

TO REACH US AT PEP

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