

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

APRIL 2017

Barbara Marquardt, Editor, M.Ed., MCHES, WCP, RYT

APRIL MEETING

Wednesday, April 5, 2017 – 2 p.m. till 4 p.m.

Darlene Sullivan and Tonya Guy from Canines Partners for Life will speak about how their organization trains service dogs to assist individuals with a wide range of physical and cognitive disabilities including individuals with Parkinson's. Their service dogs are able to provide balance/support while walking, assist with transfers from a wheel chair to a chair/bed, retrieve items, carry items, open/close doors, pay cashiers, and more! They are in Cleveland as they are attending the Cleveland International Film Festival. One of their service dog teams are also featured in a movie .

Cleveland Heights Recreation Center / One Monticello Boulevard, Cleveland Heights, OH
(Last names N through Z, please bring light refreshments)

From David Brandt

There are a number of Parkinson's related events coming up in the next several months. I wanted to list them here in chronological order so that you can plan on attending those that hold an interest for you.

- April 2, 1-3 p.m. **The Inspiration of Lamed Vav:** Art -Medicine-Creativity Brought together by their common diagnosis of Parkinson's disease, artist Peter Leventhal and local physician Karen Jaffe join with movement disorder specialists for a program connecting creativity, medicine, and Jewish genetics. Free – Location: The Temple-Tifereth Israel, 26000 Shaker Blvd., Beachwood. Email skoletsky@ttti.org for reservations.
- April 7, Noon-1 p.m. **National Parkinson Foundation Ohio** presents Dealing With Depression & Anxiety with Parkinson's with Jeffrey Janata, PHD, Division Chief of Psychology at University Hospitals. Location: Independence Public Library. For registration, call 614-480-1901.
- April 13, 6:30-8 p.m. **The Cleveland Clinic** presents Health Talks: Battling Parkinson's Disease They will address new medical treatments, surgical options, and the effects of exercise on the brains of patients with PD. Location: Cleveland Clinic Twinsburg Family Health & Surgery Center, 8701 Darrow Rd., Twinsburg. Call 216-444-3641 for reservations.
- April 22, 10 a.m.-2:30 p.m. **Ohio Parkinson Foundation Northeast Region** presents their 19th Annual Parkinson Symposium featuring talks by Heather Zwickey, PHD talking on Food as Medicine and Dr. Ben Walters, Director Parkinson's and Movement Disorder Center, University Hospitals talking on Developments in PD Management. No charge and a free lunch is provided. *PEP* will also have a table there. Call 800-630-3193 for reservations.
- June 17 **Moving Day Cleveland** at Wade Oval in University Circle. After a very successful inaugural Moving Day last year, the event is back at Wade Oval. I am looking for a volunteer to organize a team from *PEP* to walk in the event. Please let me know if you are interested.
- June 26, 2 p.m. **National Parkinson Foundation Ohio** presents Parkinson's Caregiver Training for assisting your loved one. Come to learn the safest techniques for lifts and transfers in chairs, in bed, in the bathroom, and in the car. All caregivers will leave with a gait belt and a Caregiver Workbook. Led by Faith Gilbert, PT, SSF. Location: InMotion in Warrensville Hts. Call 614-890-1901 for reservations.

PEP May Meeting – May 3, 2017

We welcome Shalom Plotkin from Right at Home which specializes in providing in-home care and assistance, and will speak on How to Prevent Falls. As we reach older age, falls can be devastating – this talk will help explain how to avoid falling in the home or how to assist your loved ones to stay safe in their homes.

Cancer Drug That Might Slow Parkinson's, Alzheimer's Headed For Bigger Tests

(Excerpt from All Things Considered, Jon Hamilton)

Scientists are hoping that a single drug can treat two devastating brain diseases: Parkinson's and Alzheimer's.

The drug is nilotinib, which is approved to treat a form of leukemia.

In late 2015, researchers at Georgetown University Medical Center found that small doses of the drug appeared to help a handful of people with Parkinson's disease and a related form of dementia. They'd tried the unlikely treatment because they knew nilotinib triggered cells to get rid of faulty components — including the ones associated with several brain diseases.

Results of that preliminary study generated a lot of excitement because there is currently no treatment that can slow or halt the brain damage caused by either Parkinson's or Alzheimer's.

Many researchers were cautious, though. "It was such a small trial, there was no placebo control and it really wasn't designed to assess efficacy," says J. Paul Taylor, chair of the cell and molecular biology department at St. Jude Children's Research Hospital in Memphis.

So Georgetown is launching two larger and more rigorous trials of nilotinib, both designed with input from the Food and Drug Administration. One of the trials will enroll 75 patients with Parkinson's disease, the other will enroll 42 patients with Alzheimer's.

Nilotinib seems to work by eliminating toxic proteins that build up in the brains of people with Parkinson's and Alzheimer's. The drug activates a mechanism in brain cells that acts like a sort of garbage disposal.

The primary goal of the studies is to learn whether this powerful cancer drug is safe enough for patients with brain diseases. But the new studies should also provide better evidence about whether the drug really works.

There's good reason for patients with Parkinson's, Alzheimer's and other neurodegenerative diseases to be optimistic these days, Taylor says — Drugs like nilotinib are coming along because years of research have provided a much better understanding of how these damage the brain, he says. "Now we're in the payoff phase."

Taylor still isn't sure whether nilotinib will live up to its early promise. But, he says, "If the results of this trial don't

turn out to be as exciting as the very tiny trial suggested, I would not get too pessimistic because there are other developments that are in the wings."

The Georgetown studies are enrolling patients now and will take more than a year to complete.

TRIBUTES

Ida Howze

Andreas Koustis

Rudolph Kuchenmeister

John and Minna Mortensen

Sylvia Steen and Valerie Schloss

83-Year-Old Invents Parkinson's 'Retainer' to Deliver Oral Levodopa Via the Mouth

(Excerpt from parkinsonslife.eu)

A tiny, non-invasive pump that clips onto teeth could be the first device to continuously deliver oral levodopa to people with Parkinson's

"I would love to see the device widely used by people, while I'm still alive," says Dr. Adam Heller.

The 83-year-old research professor at the University of Texas, US, who has more than 260 US patents, now claims to have developed the first device for Parkinson's patients, which continually delivers oral levodopa and carbidopa at a controlled rate.

His invention aims to reduce the periods of uncontrollable and fluctuating symptoms — known as 'off' periods — that many people with Parkinson's experience as a result of using oral levodopa and carbidopa in tablet form.

The small device, called OraFuse™, consists of a disposable, propellant-driven drug pump, fixed to a reusable custom-fit retainer that clips onto the upper back teeth and rests on the roof of the mouth. According to Dr. Heller, this method can replace the single large, short-acting dose of a levodopa pill with continual, steady micro-doses of the oral form, therefore decreasing the risk of under-dosing or over-dosing — both of which can be harmful to a patient.

To use the device the user inserts a new drug pump into the retainer, removes the cap to start the flow of the drug and then places the retainer over the teeth.

The drug is continuously released in small drips to the back of the mouth, where it is swallowed with the saliva and absorbed when it reaches the digestive system. (see pg. 3)

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: Could Hyperbaric Oxygen Treatment help PD symptoms?

Answer: Yes, great question for Parkinson's Awareness Month! First, Hyperbaric Oxygen Treatment (HBOT) is the most efficient method of transporting oxygen to cells throughout the body. This increased level of accessible oxygen provides numerous benefits, making HBOT an exceptionally effective treatment for a wide range of health conditions, including Parkinson's disease.

Another benefit of HBOT is rejuvenation of stem cells. Studies show that after just one hyperbaric oxygen treatment, concentrations of circulating stem cells doubled, and after a full course, there was an eight-fold increase.

During a hyperbaric oxygen treatment session, you sit or recline comfortably in a pressurized chamber while breathing 100% oxygen through a mask. You can listen to music, read, watch a movie or simply relax.

As the chamber is pressurized, you may notice increased pressure in your ears – a feeling similar to that of a flight landing – but there is no other discomfort. When the hyperbaric oxygen treatment session ends, the pressure slowly returns to normal. A typical hyperbaric oxygen treatment session lasts 45 minutes to two hours. Treatments are repeated, depending on the condition, anywhere from five to 40 times.

Hyperbaric oxygen therapy (HBOT) works wonders with lasting benefits. HBOT slows neuronal degeneration, mobilizes rejuvenating stem cells and enhances angiogenesis (the growth of new blood vessels that nurture damaged areas).

HBOT Locations:

- Affinity Medical Center
- Akron General Medical Center
- Alliance Community Hospital
- Ashtabula County Medical Center
- Bedford Medical Center
- Humility of Mary Health Partners
- Lutheran Hospital
- Marymount Hospital
- MedCentral Mansfield Hospital
- Mercy Medical Center
- South Pointe Hospital
- St. Elizabeth Health Center
- St. Vincent Charity Hospital
- Summa Health System
- Trumbull Memorial Hospital
- Or check, www.hyperbariclink.com

As always, thank you for your question!

Ref.: <https://www.drwhitaker.com/new-treatments-for-parkinsons-disease>

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.

83-Year-Old Invents Parkinson's 'Retainer' to Deliver Oral Levodopa Via the Mouth

(cont'd from pg. 2)

Dr. Heller told the Texas-based news station KXAN: "This is the first example where we can continuously pump a conventional solid drug into the mouth and we hope that this is just the beginning of pumping all of the drugs that are short-acting, which people need continuously."

In 2008, Dr. Heller was awarded the National Medal of Technology and Innovation, the highest technology award in the United States, by the then President, George W. Bush. He has since been working with a team of global Parkinson's specialists to develop OraFuse™ and conduct clinical trials to gain scientific insight into the device.

Dr. Heller and his team recently conducted a phase IIa study in to compare continuous oral administration of levodopa or carbidopa, versus standard levodopa or carbidopa tablets taken four to eight times daily. According to the study's published results, patients with advanced Parkinson's disease using the device experienced a 43% reduction in 'off' periods.

The development team behind the device, SynAgile, predict that the device will be available for use in three years' time.

Dr. Adam Heller is research professor at the John J. McKetta Department of Chemical Engineering at the University at Texas at Austin, US. He established the field of electrical wiring of enzymes (1988–2005) and in 2008 was awarded the National Medal of Technology and Innovation, the highest technology award in the United States. He has over 260 issued US patents and 392 pending.

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



TO REACH US AT PEP – 440-742-0153 –
dbrandtpep@gmail.com • www.ohparkinson.org
Facebook – Parkinson Education Program of Greater Cleveland

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.

Acorda Speeds Toward Filing of Parkinson's Drug

(Excerpt from www.biopharmadive.com)

Dive Brief:

Acorda Therapeutics announced Thursday morning that a Phase 3 trial of its Parkinson's disease drug CVT-301 showed a statistically significant improvement in motor function compared to placebo.

The biotech intends to file for approval of the inhalable levodopa with the Food and Drug Administration sometime in the second quarter.

Acorda is also conducting two long-term studies to assess the safety profile of CVT-30. Twelve-month data is expected later in the first quarter.

Acorda is moving swiftly to file for approval of its levodopa reformulation. The company announced positive results from the SPAN-PD trial on Feb. 9 which showed improvement in the Unified Parkinson's Disease Rating Scale-Part 3 (UPDRS III) score relative to placebo at 30 minutes post-treatment.

While oral levodopa is a common treatment for the disease, Acorda believes that the inhalable version can offer patients a more rapid onset of treatment and more reliable delivery.

The treatment is meant for patients who have "off" episodes, or periods when Parkinson's symptoms flare up.

The company will report the full results at an upcoming medical meeting and expects to file for approval in Europe before the end of the year.