

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

JULY 2015

Dr. Mark Lewine, Editor

JULY MEETING

Wednesday, July 1, 2015 – 2:00 p.m. till 4 p.m.

We welcome Werner Geldenhuys, PhD and Associate Professor and Lindsey Loftus, Senior Development Officer from Northeast Ohio Medical University (NEOMED) and will talk about the research effort at NEOMED and their creative approach to slowing down and stopping brain cell death that leads to Parkinson's disease. Their research has been partially funded by the Michael J. Fox Foundation.

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

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

From David Brandt

Last month's meeting featured Dr. James Leverenz, Director of the Cleveland Center for Brain Health at the Cleveland Clinic. We thank him for a very informative presentation. As a reminder, he mentioned his Biobank program that is looking for volunteers – both those with Parkinson's disease and those without. It is a program that will build up a databank of information available to use in research. If you are interested in participating, you can call 216-445-2211 or we will have some additional pamphlets at our next meeting.

Please keep in mind the Seventh Annual Boot Camp put on by University Hospitals at the John S. Knight Center in Akron on September 19, 2015.

Reminder to also please mark in your calendar on November 15, 2015 ***Come Dance With Me*** at Executive Caterers at Landerhaven. It includes a buffet brunch and music by the Swing City Big Band.

Alzheimer's Drug Shows Promise in Slowing Disease

(Excerpt from www.michaeljfox.org March 23, 2015)

On Friday morning our CEO sent around an email. Subject: **This is big!**
He was sharing news from pharmaceutical company Biogen Idec (renamed today as simply

Biogen) around an Alzheimer's drug in development with strong implications for Parkinson's research. The drug – aducanumab (BIIB037) – showed safety and positive impact not only on clinical symptoms but also on brain imaging scans.

Alzheimer's, like Parkinson's, is a disease of protein clumps. In Alzheimer's the protein amyloid-beta aggregates into what scientists call plaques. In Parkinson's disease, alpha-synuclein protein clumps to form Lewy bodies. Researchers believe these plaques and Lewy bodies harm brain cells.

Biogen compared BIIB037 to placebo in 166 people in the early stages of Alzheimer's disease. Analysis showed no change in plaques among those given the placebo, but there was significant change in those who received the drug. In fact, those given more of the drug showed greater decrease in plaques and less decline in cognitive and functional abilities.

Big news, indeed. The company is planning a Phase III study with hopes to begin later this year. (cont'd pg. 2)

PEP August Meeting – August 5, 2015

We will have our ice cream social. Please join us for fun and socializing along with various ice creams and toppings!



Alzheimer's Drug Shows Promise in Slowing Disease (cont'd from pg. 1)

What does this mean for people with Parkinson's disease?

While not everyone with Parkinson's develops dementia, some do. People with PARKINSON'S DISEASE dementia often have amyloid plaques like those seen in Alzheimer's, so a drug such as BIIB037 may benefit that population, though further testing would be necessary.

These findings are a win for Parkinson's research too, because BIIB037 is an antibody (disease fighters that help the body fend off harmful substances). Scientists are currently testing two antibody approaches against alpha-synuclein in clinical trials to slow Parkinson's progression. The positive results from this Alzheimer's study are a boost that this therapeutic strategy shows real promise.

This excitement comes with a caveat though. Biogen has a biomarker tool to measure the impact of its drug; Alzheimer's researchers can measure amyloid load in the brain through imaging capabilities. We don't have such a tool for Parkinson's research yet.

Our senior vice president of research programs, Mark Frasier, PhD, is at the International Conference on Alzheimer's and Parkinson's Diseases and Related Neurological Disorders in France, where Biogen shared its study results.

"I was at the presentation, and it was definitely impressive – both the changes on the biomarker scan but also the slowing of clinical progression. My takeaway from this entire meeting is how much we need better biomarkers of Parkinson's disease," he wrote in an email.

The Michael J. Fox Foundation is working urgently to validate Parkinson's biomarkers. We've assembled a team to develop the technology to image the alpha-synuclein protein in the brain. And the MJFF-led Parkinson's Progression Markers Initiative study is working toward measures of alpha-synuclein in blood or spinal fluid. Research toward these vital research tools is a top priority for the Foundation.

UNC Team Uses Cellular Bubbles to Deliver Parkinson's Meds Directly to Brain

(Excerpt from the National Parkinson Foundation website.)

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by cells – as vehicles to deliver a potent large-molecule drug to the brain.

Researchers at the University of North Carolina at Chapel Hill have used exosomes – tiny bubbles of protein and fat produced naturally by cells – to bypass the body's defenses and deliver a potent antioxidant directly to the brain to treat Parkinson's disease.

And what's the best way of getting her drug-packed exosomes to the brain? It looks like a simple nasal spray will do the trick, say Elena Batrakova and her colleagues at the UNC Eshelman School of Pharmacy's Center for Nanotechnology in Drug Delivery.

Batrakova and her colleagues extracted exosomes from immune cells and successfully loaded them with the enzyme catalase, a potent antioxidant that counters the neuron-killing inflammation responsible for Parkinson's and other degenerative neurological disorders. Their work was published in the *Journal of Controlled Release*.

This is the first time a large therapeutic protein like catalase has been delivered to the brain using exosomes. Getting drugs into the brain is extremely difficult in general because it is protected and isolated from the rest of the body by the blood-brain barrier, which is extremely selective about what is allowed to pass through.

Batrakova and her team at the pharmacy school harvested exosomes from macrophages, white blood cells that are responsible for clearing foreign material from the body. Exosomes are tiny spheres produced by cells to carry chemical messages. They are made of the same material that makes up cell membranes. Diseases like cancer and AIDS propagate throughout the body by hijacking exosomes.

"Exosomes are engineered by nature to be the perfect delivery vehicles for proteins and genetic material," Batrakova says. "Catalase is a huge protein, and it is almost impossible to deliver across the blood-brain barrier alone. We use exosomes from white blood cells, which are invisible to the immune system and easily interact and fuse with the blood-brain barrier to deliver their cargo across it."

Batrakova's goal is to develop personalized treatments by loading proteins into exosomes that have been extracted from a patient's own white blood cells. These packages of medicine will be ignored by the patient's immune system, which works against unknown proteins as well as many synthetic delivery vehicles.

And what's the best way of getting her drug-packed exosomes to the brain? It looks like a simple nasal spray will do the trick, Batrakova says.

Traveling

(Excerpt from National Parkinson Foundation)

Travel is accessible for many people with Parkinson's disease. The idea of planning and taking a trip may be daunting and stressful for some. However, once broken down into specific categories and questions, the task is not only manageable, but also produces fruitful and satisfying results.

FOR STARTERS

- Plan your trip carefully and in advance
- Check your medical insurance policy to be certain that you are adequately covered. Be aware of services provided (or not provided) in other countries.
- Ask your neurologist if she can give you the name of a doctor in the area to which you are traveling
- Find out if there is a National Parkinson Foundation Center, chapter, or support group in the area you are visiting
- Don't forget to rest the day before your trip AND the day (or day after) you arrive



ABOUT MEDICATIONS

- Be sure to bring your Aware in Care Parkinson's ID bracelet or wallet card with you. If you don't have an Aware in Care kit, contact NPF's free Helpline at 1-800-473-4636 while in the planning stages of your vacation.
- Carry all medication in original bottles, with the name of the drug and your doctor's name on the label
- Bring a copy of your prescriptions (generic and non-generic names) and medication regimen, including your physician's name and contact information
- Carry all your medication, for your entire trip, in your carry-on bag; include snacks, water, or juice to take with meds
- Bring a replacement supply of prescription medications in case you are detained or your supply is lost
- If you are changing time zones, continue to take your medications as prescribed, with the same intervals between doses. Consider wearing two watches: current time, and time at home.

AT TRAVEL TERMINALS

- If necessary, request wheelchair or electric cart service within terminals (your bags will be handled too!)
- Check in early
- Utilize early boarding privileges, and, if necessary, special accommodation to get to your seat

- Request an aisle seat, and as close as possible to bathroom.

AIR TRAVEL SPECIFICS

- Airline carriers must provide meet-and-assist service (e.g., assistance to gate or aircraft) at drop-off points
- Personal care assistants of passengers with disabilities are allowed beyond screener checkpoints
- The limit of one carry-on bag and one personal bag (purse) per traveler does not apply to medical supplies and/or assistive devices
- Assistive devices such as canes and wheelchairs are permitted on board
- People who require wheelchair or scooter must have physician's written "certificate of need"
- People in wheelchairs can request private, rather than public, checkpoint screenings
- With documentation of medical need, and with proper labeling, syringes are permitted on board

BUS TRAVEL SPECIFICS

- Greyhound buses are equipped with wheelchair lifts
- Greyhound provides assistance with boarding, deboarding, luggage, transfers, stowing and retrieving mobility equipment
- Greyhound allows personal attendant to travel one-way at no charge. (Arrangements for a return ticket are made at the returning location).
- Service animals, oxygen and respirators are permitted

OCEAN CRUISE SPECIFICS

- Ocean liners offer scooters for rent during cruises
- Determine in advance whether any ports of call require a license for a motorized wheelchair

HOTELS

- Ask specific questions. For example, what does "accessible room" actually mean? Is there a walk-in shower? Grab bars? What is the proximity to elevators?

GENERAL REMINDERS

- See fewer sites ... enjoy them more!
- Give yourself extra time for everything!
- Don't let PARKINSON'S DISEASE hold you back from the trip of your dreams! Bon Voyage!

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.

PEP NEWS

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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.



**How Pets Help
People with
Parkinson's
Disease**

(Excerpt from www.michaeljfox.org, June 12, 2014)

For many people with Parkinson's disease, pets provide both companionship and practical help with daily life.

Service dogs trained to work with people with Parkinson's can help their owners maintain balance while walking, or alert a family member after a fall.

They can also be trained to help people with Parkinson's move when experiencing gait freezing or stand up from a chair or after a fall.

Plus, owning any dog, service or not, automatically writes exercise into an owner's schedule. Research shows that regular exercise helps many people with Parkinson's disease improve symptoms. Running around with a cat also qualifies as exercise (though of course cats are better known as naptime companions!)

In general, studies link pet ownership with reducing signs of depression in people with chronic illnesses and with reducing loneliness in the elderly. In one study, residents of a nursing home felt less lonely after visiting with a dog alone than after visiting with a dog and other residents.

Interested in finding a service dog? Visit the Assistance Dogs International website <http://www.assistedoginternational.org/> to find accredited breeders in your area.

TRIBUTES

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Catherine Lauffer**

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