

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

MAY 2018

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

MAY MEETING

Wednesday, May 2, 2018 – 2 p.m. till 4 p.m.

We welcome Ben Rossi, owner of ATP Evolution Performance Training Center and Founder and Program Director of InMotion. Ben and Dan Medves from ATP will give an interactive discussion titled: **Exercise for Brain Change**. It will include Boost exercises that are designed to address specific symptoms of PD.

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

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

From David Brandt

I recently became aware of some services offered by Tri-C that may be very useful to those with Parkinson's that are unable to afford services. They are a facility that provides physical therapy, occupational therapy, medical assisting and dietetic technology services to the uninsured or underinsured through the use of their students at Tri-C and licensed professionals from the area. They would be a great source to anyone with a Parkinson diagnosis who may have maxed out their therapy benefits for the year or cannot afford their co-pays. They would love to offer their services to any or all who may need them.

Some services are offered at a greatly reduced price while others such as dietary consultation come with no charge at all. You can find out more by calling Heidi Shenk, PT, Liaison, Preventative Care Center Cuyahoga Community College Metro Campus at 216-987-3555. They do not require a doctor's referral to provide service.

Here are some upcoming Parkinson's related events:

April 28 – Best Day of the Year Foundation presents Fight Night, a fight against Parkinson's Disease in honor and support of David Fisher. Brian "Beefcake"

Munday will square off against Dave "Best Day of the Year" in a match after two other real bouts. This will occur at the 2 Tone Boxing Club located at 23307 Commerce Park Dr. in Beachwood. Doors open at 6:30 p.m. and dinner and drinks are included in the \$75 general admission cost. Tickets must be bought in advance through bdotyfoundation@gmail.com.

June 23 – Moving Day Cleveland will be held at Wade Oval in University Circle. PEP will be having a team donation for this event. In next month's newsletter we will provide more details on this. It would be wonderful if our PEP Team can be among the top teams!

TO REACH US AT PEP – 440-742-0153

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Facebook – Parkinson Education Program of Greater Cleveland

TRIBUTES

Nancy Tyburski

YourCause, LLC Trustee for MasterCard

In Memory of Raymond Brandt
Tina Pitmon

Parkinson's Pilgrimage: Hiking the Camino de Santiago for Stem Cell Research

(Excerpt from parkinsonslife.eu)

The Summit For Stem Cell Foundation is inviting the Parkinson's community to join them on their Camino de Santiago pilgrimage hike to raise money for stem cell projects

The stem cell research organization Summit For Stem Cell Foundation has raised US \$5.5 million for Parkinson's research – and is now aiming to raise a further US \$8 million to see through stem cell transplantations in 10 Parkinson's patients.

To help achieve the two-year fundraising target, the US-based foundation is inviting people from the Parkinson's community to join them on their eight-day trek, from October 3 to 11, 2018. This year they will be hiking the Camino Inglés, which is one of the least travelled routes on the Camino de Santiago pilgrimage trail in Spain.

Sherrie Gould, founder and movement disorders advisor, Summit For Stem Cell, says: "We've had 33 people sign up so far and have 27 spots left. We'll have a bi-lingual English and Spanish speaking guide for every 10 people.

"We are really hoping that we'll get people signing up to help our cause from Europe, as it's right on your doorstep." She says budgets for the trip are still being finalized, but the cost is likely to be US \$1,500.

Sherrie is keen to stress that anyone participating with Parkinson's must also have a 'buddy'. The buddy will be responsible for their partner, assisting them if they need to stop or go home sooner.

This is the fourth trek organized by the Summit For Stem Cell Foundation. A team climbed Mount Kilimanjaro in 2011 and reached base camp at Mount Everest in 2013.

In 2016, we reported on how the Summit team, with the help of guides and pack horses, hiked for more than 30 miles over seven days to the summit of Machu Picchu, Peru – raising over US \$120,000 in

funds for research.

She says those who sign up for the hike will receive regular email updates with advice on how best to train and prepare themselves. "People will be able to see how many miles we're doing and they will have a whole hiking schedule. My dream is to hold hands and join forces with the Parkinson's community in Europe."

The project began in July 2010 when medical professionals from The Scripps Research Institute and Scripps Clinic, San Diego, CA, and the Parkinson's Disease and Other Movement Disorders Center, La Jolla, CA, collaborated on Parkinson's research using stem cells. Extensive funding was needed to support clinical trials.

The organization has since raised millions of dollars, with 97% of all donations going directly to research. They are able to keep overheads low as everyone working for the organization does so voluntarily – apart from the scientists carrying out the research.

Sherrie says: "We have catheters that we want to use to transplant the cells into the brains of our patients. So, right now we're testing those catheters in a petri dish. We must wait for approval from the US Food and Drug Administration (FDA) approval before clinical trials start, but we are hoping for early 2019."

The Summit For Stem Cell Foundation is part of a collective called G-Force PD, which involves five of the leading stem cell research teams from Europe, Japan and the US.

Sherrie says: "The whole concept of the group is for people to get together and just discuss problems. You know, people are coming with solutions, as a team we learn from each other, we discover how we can help each other and discuss the roadmap to the clinic."

For comprehensive information about stem cell treatment please visit the European Parkinson's Disease Association (EPDA) [website](#).

To sign up for the trek visit the Summit For Stem Cell [website](#)

Read more: [VIDEO: Parkinson's stem cell treatments explained in just 90 seconds](#)
[Climbing Machu Picchu to conquer Parkinson's](#)

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: What test could I take to see if I have a Parkinson's gene?

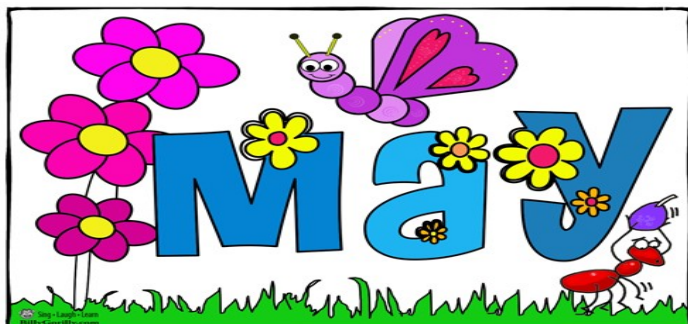
Answer: Great question! The at-home test I would suggest is 23andMe. It consists of three easy steps. First, order the Health and Ancestry kit. Your saliva collection kit will arrive in three to five days. Second, follow the kit instructions to spit in the tube provided, all from your home. Register your saliva collection tube using the barcode so 23andMe knows it belongs to you, and mail it back to the 23andMe lab in the pre-paid package. In approximately six to eight weeks, 23andMe will send you an email to let you know your reports are ready in your online account. Log in, and start discovering what your DNA says about you.

Learn about your Genetic Health Risks (meets FDA requirements) learn how your genetics can influence your risk for certain diseases, your Ancestry, learn where your DNA is from out of 150+ regions worldwide and more, your Wellness, learn how your genes play a role in your well-being and lifestyle choices, your Carrier Status (meets FDA requirements) learn if you are a carrier for certain inherited conditions, and your Traits, learn how your DNA influences your facial features, taste, smell, and other traits.

In 2017, 23andMe collaborated with The Michael J. Fox Foundation for Parkinson's Research to enable genetic data collection and sharing with qualified researchers through the Fox Insight Genetic Sub-study. Results will let you know if you have the LRRK2 genetic mutation.

You could purchase online at 23and Me, or at retail stores such as Best Buy, CVS Pharmacy, Target, Walgreens and Walmart. The cost is \$199.

Go to www.23andme.com or call 1-800-239-5230.



Excess Calcium in Brain could Cause Parkinson's

(Excerpt from parkinsonslife.eu)

Researchers at the University of Cambridge, UK, have discovered that excess levels of calcium in brain cells may lead to the formation of the toxic clusters that signify Parkinson's disease.

The findings, reported in the journal '*Nature Communications*', show that calcium can influence the interaction between small membranous structures inside nerve endings, which are important for neuronal signaling in the brain, and alpha-synuclein – the protein associated with Parkinson's disease.

Dr. Janin Lautenschläger, the paper's first author, said: "This is the first time we've seen that calcium influences the way alpha-synuclein interacts with synaptic vesicles. We think that alpha-synuclein is almost like a calcium sensor. In the presence of calcium, it changes its structure and how it interacts with its environment, which is likely very important for its normal function."



PEP June Meeting – June 6, 2018

We welcome Lisa Wunderle, Therapy Consultant, of Boston Scientific who has been involved with the Parkinson's community for 8 years and will talk on Deep Brain Stimulation, how it may help, who is a good candidate, what questions to ask your doctor.

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

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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.

Effects on Functional Brain Activity of Four Weeks' Supplementation with a Multivitamin and Mineral Supplement

(Excerpt from www.naturalnews.com)

Nutritionists have concluded that multivitamin and mineral supplementation can dramatically improve mood and brain activity in only four weeks. These findings, published in the Journal of Nutrition & Intermediary Metabolism, suggest that the continual consumption of multivitamins can benefit neurocognitive function.

- Fifty-eight healthy adults, with a mean age of 26, were analyzed in a randomized, double-blind, placebo-controlled study.
- Blood biomarkers and functional brain activity were assessed at baseline and after four weeks supplementation.
- Participants displayed higher levels of B-vitamin along with a significantly lowered homocysteine count after the experiment period.

Partial grant support provided by OPFNE



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- These measurements are associated with improved mood and mental well-being.
- This was further highlighted by the notable reduction of the participants' scores on the depression-dejection subscale of the Profile of Mood States.
- Brain scans likewise revealed that working memory was more activated after four weeks of multivitamin supplementation.

The authors of the new study conclude that multivitamin supplementation can positively affect brain function, altering neurocognitive activity in healthy young adults.

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.