Indy PD Update

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Parkinson's Awareness Association of Central Indiana, Inc.

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Symposium 2017

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Sign up for our Friday E-blast

Did you know that most time sensitive information is sent out through our Friday e-mail e-blasts? If you would like to receive messages from us that include information about new or updated PD info, local events, or webcasts please be sure to share your email with us by emailing skauffman@paaci.org and put Friday E-blast in the topic line or call Sheri at 317-255-1993.

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Thank you!!!

The PAACI Board wishes to express our appreciation to outgoing board member Nancy Pressner and her family for their years of dedicated support.

Newsletter

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Arranged & Edited by Sheri Kauffman, John Deck & Susan Szep

Helpful Phone Numbers

Movement Disorder Specialists

Ruth Ann Baird, M.D.—317-217-3000
Joanne Wojcieszek, M.D.—317-944-4000
Liz Zauber, M.D.—317-944-4000
Christopher James, M.D.—317-948-5450

PAACI Office—317-255-1993

American Parkinson's Disease Assoc.-800-223-2732

Aqua/Swim classes—317-547-8349

Caregivers Spt Grp w/Catholic Charities—317-261-3378

CICOA—317-254-5465

Chair exercise classes—317-872-4567

EquiLibrium Yoga Therapy (Bloomington) 812-331-7423

Ft. Wayne exercise classes—260-486-4893

Indiana Parkinson's Foundation & The Climb—317-550-5648

Indiana Reading & Information Services—317-715-2004

National Parkinson's Foundation-1-800-473-4636

Parkinson's Action Network—800-850-4726

Parkinson's Disease Foundation- 212-923-4700

Rock Steady Boxing—317-205-9198

Rx for Indiana—1-877-793-0765

Shelby County PD Exercise & Support—317-398-7614
(Currently limited to Shelby County residents and Major Health Partners patients)

Debunking Major Myths in the Treatment of Parkinson's Disease

Presented by: Alberto J. Espay, M.D. at the 2017 Parkinson's Symposium

Dr. Espay started his presentation stating that a lot of the way we practice the treatment of Parkinson's Disease is based on dogma or mythology. Noting that he wants to present information on how we can move in a different direction.

FACT: The way we currently treat Parkinson's is simple. We are replenishing a system that has a dopamine deficiency. Many times dopamine agonists are prescribed initially to help relieve the early symptoms of PD. Dopamine agonists are synthetic molecules meant to affect dopamine receptors, however they are less effective than levodopa and have a variety of side effects. Since dopamine is the problematic molecule the best way to replace dopamine is by taking levodopa.

FACT: Levodopa never stops working. However, the efficiency of the system that processes the dopamine is weakened over time. You must increase the dosage of dopamine over time as the system becomes less efficient.

MYTH: The common myth is the longer you delay taking levodopa the less dyskinesia you have.
FACT: Each patient seems to disprove this myth. Delaying levodopa doesn't delay dyskinesia. It is about when the "disease clock" starts resulting in levodopa induced dyskinesia.
FACT: We now know if we give levodopa in a tonic not phasic form (the method of delivery), mirroring what really goes on in the brain, you do not have these side effects.
FACT: The purpose of taking levodopa is to elevate the dopamine level. We have yet to make progress in reversing or finding a cure for the disease.

FACT: We are looking for a "common denominator" (finding a characteristic that is shared by those who have the disease) of the cause of the disease.
FACT: Parkinson's is different for each person. There are those with rapid disability, low survival, and early dementia; and those with long survival, slow disability, and little dementia. The "PD script" is not the same for everyone. PD symptoms are as varied as the individuals diagnosed with it.

FACT: Parkinson's can occur as a result of a variety of different abnormalities including; inflammatory mechanism, mitrochondrial mechanism, calcium homeostasis, synaptic pathology, failure of protein degradation, and apoptosis (programmed cell death). All of these types have Lewy bodies (abnormal deposits of proteins that develop inside nerve cells and displace other cell components); and dopamine deficiency. Could it be pathogenic (caused by bacteria or disease)? Is this the common denominator?

FACT: Every single thing we've done to change the disease has failed. Traditional medicine uses symptoms to diagnose diseases and drugs to treat these symptoms. This reductionist approach attempts to reduce the complexities to less complex units. (Ref. Medical News Today: Precision Medicine: from "One Size Fits All" to personalized healthcare by Yella Hewings-Martin Ph.D., October 25, 2017)

Proteasomal dysfunction: Dr. Espay gave an example of proteasomal dysfunction, noting that individuals may have specific problems with their proteins gathering. If we find something that affects these pathways in a positive way, then we now have a therapy that may help everyone, but it needs to be tested. At this point, we conduct a clinical trial using the approach of the current clinical trial model and we often get a negative result.

Precision Medicine is a way of looking at a disease model's molecular driven subtype. The idea is that the physician would be able to do a test that would assess more specifically your Parkinson's and then he could treat you with a molecular approach.

Continued on page 4

Biomarker development is used in precision medicine to tell us something meaningful about your PD. Dr. Espay showed a slide demonstrating the current model of biomarker validation. We need to look for molecular biological truths about the disease. With the precision medicine model we would be able to biologically describe "your" particular Parkinson's disease.

MYTH: Tremor is a significant correlation for PD.
FACT: There are many, many subtypes of PD, and many of them do not have tremor.

FACT: We need to change our way of thinking about aging, brain aging, and Parkinson's Disease.

We need to do studies on aging, using a large population of individuals with and without neurological disease. We can look at the biomarkers (outliers) which are way above or below normal.

The future of clinical trials will have fewer subjects, but characterized by molecular biological information. It is important that we move toward this molecular approach. We are currently in the early stages of a new research design for Parkinson's that could offer molecular based treatments for the many subtypes.

Currently $9.75 of every $10.00 of Parkinson's research funding is going toward the old model. He shared that it is up to the Parkinson's community to encourage this new approach (precision medicine) for research. We need to redefine Parkinson's as based on molecular science.

MYTH: Stem cell therapy was a miracle when it happened. Stem cells are not capable of producing the right kind of dopamine. However, because of the placebo effect (stem cell therapy vs. placebo) the benefit was positive for all involved.

MYTH: There's nothing I can do to can make my PD better.
FACT: PD patients who exercise on a stationary tandem bicycle during a single 40 minute sessions experience a 35% improvement in motor function and increased brain activation similar to that found with levodopa treatment.

MYTH: Clinical trials are not important.
FACT: Progress is impossible without active roles of doctors and patients. Currently enrollment in studies is less than 1% of the Parkinson's population.

Lessons Dr. Espay has learned from clinical trials:

1. L-dopa-induced dyskinesia is a misnomer. It is related to how it is administered.
2. Dopamine agonists do not delay dyskinesia. They are not as effective as L-dopa and can cause additional disabilities.
3. Not having dyskinesia is preferable to everyone.

FACT: The year 2017 is the 200th anniversary of Dr. James Parkinson's writing the definitive work, "The Shaking Palsy."

Dr. Espay believes we will be finding many subtypes of Parkinsons's in the future. He is part of the Parkinson's Study Group, which is the oldest organization of Parkinson's research in America.

Questions & Answers:

1. **Why are we so slow in changing our approach to studying PD?**
   A: We have held onto Parkinson's the way it is. We have the alpha syneuclean theory, which tells us how it evolves. It is because we try to get easy answers quick. Changing this is not easy since we are saying that if we cannot figure out the molecular biology, we will never find a cure. We need to quit thinking of Parkinson's as a syndrome, but as a collection of diseases.

2. **How do you get involved in a clinical trial?**
   A: Not all clinical trials are healthy for everyone. Most clinical trials are looking for symptomatic benefits and not everyone will have the symptoms being studied.

3. **Do you see an increase in incidence of the Parkinson's syndrome in the general public?**
   A: Yes, but that's probably due to increased aging.

4. **Do you hold any hope from data provided by imaging studies?**
A: Not at this time, because they look at things that are common in a diverse population.

5. **Is there a way to tell if you are volunteering for studies that are a better way of investigating the disease?**
A: Yes, ask yourself "How was the patient population selection made for this study?" If you meet the criteria for the study based on your doctors ability to check what you have, then it's the same as studies done in the past.

6. **Are there other clinics/groups doing research like you are?**
A: A variety of other clinics are changing their strategies for research. Dr. Espay shared that his clinic and the Cleveland Clinic are setting up a biomarkers study that will involve 10,000 subjects.

7. **Is there a way the general public can promote this form of research?**
A: Encourage others to check the work of the Parkinson's Study Group.

Thanks to all our sponsors & volunteers!

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Using Music to Improve Your Health

As presented by Brenda Kenyon, MSW, LCSW. BM, Music Therapist

What is Music Therapy? Music therapy is the clinical and evidenced-based use of music to accomplish individual goals within a therapeutic relationship. A music therapist must be a credentialed professional who has completed an approved music therapy program. Board certified music therapists utilize music in a therapeutic structure to address physical, emotional, cognitive, and social needs. It is highly personalized, and the focus may be on the individual's physical, emotional and/or spiritual needs and concerns.

Music as therapy is offered by a trained, degreed, Board-Certified Music Therapist. The therapist will work with an individual using all forms of music to address their specific problems or goals as decided between the therapist and client.

Each individual decides what they want to do with their music therapist. This may include:

1. Entertainment and sensory application for gross and fine motor movement (such as dancing)
2. Listening to live or recorded music
3. Playing an instrument
4. Singing and vocalizations
5. Improvisation (such as a piece of music, drama, etc., that's created without preparation)

How can music therapy help me?
Neurologic music therapy is a specialized field that is research based and has been found to positively impact symptoms of Parkinson's Disease and other neurological illnesses.

Music and Parkinson's Disease
Music has been shown to activate widely distributed cortical and subcortical networks in the brain related to motor, sensory, and cognitive functions. There is no "music center "in the brain, but rather "multi-modal brain areas that mediate in general cognitive and motor control centers." There is strong evidence that music shares processing centers with speech and language functions in the brain.

The therapeutic application of music can be used to address cognitive, affective sensory, language and motor dysfunctions due to disease or injury to the human nervous system. A music therapist works within the interdisciplinary team to address goals. Research now supports 20 scientifically based techniques that help areas of concern for those adapting to a Parkinson's diagnosis. Some of the 20 areas include: speech, language communication, cognitive challenges in memory, sequential thoughts and organization, emotional expression and psychological support. All of these aid with adaptation and coping skills and social support in maintaining connection to others.

You Can Improve if you Move
There is a distinct neuronal connection between auditory processing and motor symptoms via connections between the brain stem and spinal chord. "Music processing can engage, train, and restrain, non-musical brain activities and behaviors." Music process can motivate and support the hard work of rehabilitation.

Music can support gait and balance work
Rhythmic auditory stimulation can set a tempo for steps, arm swinging, stops and turns. Rhythm/music brings other areas of the brain to work and helps retrain other areas. Music can support emotions and motivation as it lifts the spirit and provides engagement.

Singing for Respiratory Strength and Health

-Therapeutic singing encourages breath strength and control by restraining which muscles are used.
-It supports lung/breath capacity.
-Music impacts cognitive abilities

-Music can help ease pain through distraction, guided imagery, progressive relaxation, and mindfulness practice.
-Music connects you to memories
-Music can influence emotions
-Music offers hope
-Music connects you to others

Brenda shared that music therapy is research based, and hopes you will try it. She concluded the program by introducing the audience to Lisa Colleen from Bongo Boy. Lisa led the audience in a drum circle. All the audience members seemed to enjoy participating in this very fun form of music therapy.

Memorials:

Calvin Terry Bayles
Marcia, Miles, Davis & Blake Clutter, Marc & Betsy Smith, Bruce & Diana Bayles, Peggy Jackson, Witham Rehab Department, James & Betty Myers, Allen & Elaine Andrews, Jim & Joni Hale, Mike & Gloria Brown, Elaine Andrews, Aaron & Jessica Smith, John & Pat Graves, Gregory & Lisa Bye, Barbara Knell, Robert & Shirley Thompson Jr., Tanya Clawson, John Deck

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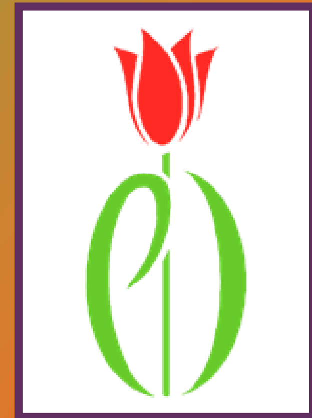
Parkinson's Awareness Association of Central Indiana, Inc. (PAACI)
P.O. Box 19575, Indpls., IN 46219
317-255-1993 www.paaci.org
Facebook: Indianapolis Parkinson
Email: skauffman@paaci.org



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