

Indy PD Update

PRODUCED AND DISTRIBUTED BY: PAACI
Parkinson's Awareness Association of Central Indiana, Inc.

July, 2019—September, 2019

Upcoming Parkinson's Events:

Future 2019 Events—Save the date!!!

Thursday, August 15, 2019 @ 6 pm

Dinner with Mary Scott NP, RN, NSP-BC from

University of Toledo Medical Center, Gardner-McMaster Parkinson Center

Discussion about PD and Amneal's Rytary

at Ruth's Chris Keystone at the Crossing

To register please call 1-844-947-4211 or go to TakingonPD.com.

Saturday, September 14, 2019—Fall Parkinson's Symposium

Latest & Greatest Breakthroughs in PD Therapy & Purdue Research

Knights of Columbus, 2100 E. 71st St., Indpls, IN 46220

With Dr. Lawrence Elmer (Director of Parkinson's Disease and Movement

Disorders Program at the University of Toledo Medical Center) and

Jean-Christophe (Chris) Rochet, Ph.D. (Director of the Purdue Institute for

Integrative Neuroscience). Please see information about the speakers on page 8

and registration information and form on page 9.

Saturday, November 9, 2019—Caregiver Conference at MCL

2370 W. 86th St., Indpls., IN 46224

Speakers to be announced.

Saturday, December 7, 2019 —Holiday Party at MCL

2370 W. 86th St., Indpls., IN 46224

Lunch at MCL with entertainment and silent auction.

25 for 25

John Deck, president of PAACI, has participated as a volunteer and/or officer with PAACI for 25 years. In commemoration of this anniversary John is making a matching gift donation. For each donation to PAACI of \$25 dollars or more, between June 15, 2019, and November 15, 2019 John will make a \$25 matching donation. John is proud that PAACI has served the Parkinson's community with educational and support for more than 38 years and he's even more proud that he's been a part of it. Please help John celebrate his 25-year anniversary with PAACI by making a 25 for 25 donation.

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Newsletter

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Arranged & Edited by Sheri Kauffman & John Deck

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.

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

Specialized Yoga Therapy for Neurological Conditions & Movement Disorders (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

Parkinson's Action Network- 800-850-4726

Parkinson's Foundation- 1-800-473-4636 / Parkinson.org

Rock Steady Boxing—317-317-288-7035

Rx for Indiana—1-888-477-2669

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

-Young Parkinson's of Indiana (YPI)—317-203-3049

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Sheri Kauffman

Neuropsychology of Parkinson's Disease

With Mitch VanSumeren, Psy.D. and Courtney Johnson Ph.D. from Indiana University School of Medicine
Written by John Deck, Ph.D.

Movement disorders are a classification of neurologic symptoms characterized by either an increase in unwanted or involuntary movement; or a decrease in the ability to carry out voluntary movements/actions. Movement disorders are often attributable to abnormalities or dysfunction of the basal ganglia area of the brain. They are composed of nuclei below the anterior neocortex and include the putamen, globus pallidus, caudate nucleus, subthalamic nucleus, and substantia nigra. Connections between these structures extend to the cerebral cortex, including the motor areas. When the basal ganglia is damaged, movement disorders can begin due to the disruption in the nuclei's ability to regulate movement. This can produce hyperkinetic or hypokinetic disorders.

Hyperkinetic vs. Hypokinetic

Hyperkinetic is characterized by uncontrollable movements random in nature and may include jerking movements, twitches, and writhing movement.

Hypokinetic is characterized by slowing, rigidity and disruption in the ability to initiate and completed planned motor movements. Too little force results in inadequate movement. Parkinson's disease is an example.

Symptoms of Parkinson's Disease (PD)

PD arises as a result of a degeneration of the substantia nigra and subsequent death of pigmented neurons that reside within, causing a reduction in the levels of dopamine the neurotransmitter produces within the neurons. These neurons make the dopamine. The substantia nigra loses its black coloration. The symptoms of PD arise following the loss of approximately 70% of dopamine producing cells in the substantia nigra.

The symptoms arise gradually. Sometimes the earliest symptom is hand tremor and stiffness. As the disease progresses, physical symptoms may vary but are typically comprised of four major types: tremor, rigidity, akinesia, and postural reflex disturbances (loss of the ability to carry out motor movements).

Positive and Negative Symptoms:

A positive symptom may include the onset of abnormal behaviors such as resting tremors, muscle rigidity, and involuntary movements. Negative symptoms may include a loss of or difficulty with normal behaviors such as posture, righting (making minor adjustments in compensatory movements), walking, speech disturbances, and slowness or movements (akinesia). PD usually has physical symptoms first.

Cognitive Changes in PD

Cognition is the mental actions we use to learn and do. With Parkinson's there can be diminished:

1. Bradyphrenia: slower brain functions
2. Executive functioning: problem solving, abstraction, including retrieval of information.
3. Attention: trouble attending to and learning new information
4. Slowed speed of processing
5. Visuospatial perception: judging distances
6. Language: written and spoken, word finding difficulties (changes in speech and language can be a side effect of deep brain stimulation).

Other causes of cognitive changes may include:

1. Aging
2. Coexisting conditions such as hypertension, diabetes, vascular changes, and pain.
3. Depression/Anxiety: can slow thinking processes
4. Sleep problems/fatigue

Compensatory Strategies (what you can change)

1. Executive Functioning:
 - a. Provide structure: use calendars, reminders and alerts
 - b. Assist with organization: have assigned places for important items or documents. Be consistent with these places
 - c. Develop systems/routine (particularly with medications)

- d. Break down decisions or tasks into smaller parts
 - e. Rank order tasks by importance and urgency. Don't try to do too many things at one time
 - f. Check in about possible feelings of being overwhelmed.
2. Attention/Memory
 - a. Eliminate distractions (too much noise such as TV or music) during important conversation or events
 - b. Ask (in advance) to audio record information shared at medical appointments or ask for a written summary with recommendations.
 - c. Consider if there is a time of day that is best for certain events or conversations
 - d. Shorten duration of time to work on tasks (work in intervals)
 3. Speech Processing/Language
 - a. Slow down speech rate (as needed)
 - b. Pause frequently in conversation
 - c. Allow for extra time to complete tasks (rushing someone can increase stress and risk for falls/errors, etc.)

Coping with Cognitive Changes in PD

Consider that errors made are not intentional (this can help reduce the frustration or taking mistakes personally). Discuss important decisions early (have a plan in advance). Monitor for when increased assistance may be needed (the person with PD may not agree with the timing). Check in with the person with PD on their sense of what is most difficult, and work together to implement compensatory strategies. Neuropsychological testing may be beneficial. It can rule out dementia, evaluate capacity, and establish a baseline for later comparisons such as mild cognitive impairment (MCI) vs. Parkinson's Disorder Dementia (PDD).

Depression and Anxiety

Major Depressive Disorder may include:

1. Depressed mood
2. Decrease interest in activities
3. Change in weight
4. Change in sleep
5. Increased restlessness or slowing down
6. Fatigue or loss of energy
7. Feeling of worthlessness or inappropriate guilt
8. Trouble concentrating or making decisions
9. Thoughts of death or suicidal ideation

Generalized anxiety disorder may include:

1. Restlessness, feeling keyed up
2. Easily fatigued
3. Trouble concentrating or mind going blank
4. Irritability
5. Muscle tension
6. Change in sleep



There is some overlap in symptoms of depression and anxiety. How common are they? Forty percent or more of people with PD may have depression. Depression in PD is often underdiagnosed. Symptoms are usually mild to moderate. Symptoms may include feelings of sadness, anhedonia (less feeling of pleasure), guilt, and concentration difficulties. There can be an anxiety component.

Anxiety: Forty percent of people with PD may have anxiety. It often co-occurs with depression. Anxiety is less well researched, and some researchers argue that anxiety symptoms are a component of depression instead of a separate entity.

What might anxiety look like in PD?

Generalized anxiety disorder (GAD) most common, followed by panic attack and phobias (social phobia) may include:

1. Worrying about disease progression or finances
2. Worrying about spilling food when out to eat or concern about other's noticing tremor. Facial expression may change with PD and this may distract from how others perceive your meaning.

Self-Care Considerations

Practical tips for good mental health: stay active, mentally and physically

1. Exercise helps the brain use dopamine more effectively
2. Talk with others: family, friends, a therapist, and join a support group.
3. Relaxation Training

Dr. Johnson recommend (book) "Mind Over Mood: Change How you feel by Changing the Way You Think," by Dennis Grenberger and Christin A. Padesky (2015) Available in paperback or check with your local library.

Exercise:

Exercise can have positive benefits for not only physical functioning and mood, but also cognition.

1. Acute aerobic exercise shows favorable effects on cognition in neurologically healthy individuals.
2. In a study assessing PD patients, high intensity interval training (HIT) showed improved immediate auditory memory, basic attention, and sustained attention.
3. Moderate intensity training (MIT) showed improved immediate auditory memory.
4. Aerobic exercise can help to promote better cognitive performance in people with PD.
5. There is still insufficient evidence to definitely say that one exercise modality is superior to another in improving cognition and/or gait.

Note: A Neurology Physical Therapist will teach you how to fall with less likelihood of injury.

Cognitive Training: There has been limited research. The current body of research reports that cognitive training is safe, and modestly effective in people with mild to moderate PD. Further research is needed, though it is just as important to exercise your brain as it is to exercise your body.

Social Activities are important, and they may include group exercise classes, support groups, time with family, time with friends, church, community groups, volunteering, and hobby-based clubs/groups.

Deep Breathing can help. This may include diaphragmatic breathing, belly breathing, which activated the parasympathetic nervous system, eliciting feelings of calm in the body. You focus on breathing air into the upper belly until full. Exhale out slowly, pausing between cycles. Deep breathing can help with pain.

Progressive Muscle Relaxation: By gently tensing and releasing muscle groups, from toes up to the forehead, note the sensations of tension and release of tension throughout the body. It helps you identify areas of your body holding tension.

Deep Brain Stimulation (DBS)

DBS is the implantation of electrodes into specific brain regions that are emitting abnormal electrical firing. DBS assists in restoring more normal signal patterns. It helps reduce severity of motor symptoms and improves muscle tone. The target areas vary depending on symptoms and may include the subthalamic nucleus (STN-most common target); globus pallidus interna (GPI); and ventralis Intermedialis (VIM).

Questions and Answers**1. What is a Neuropsychological Examination?**

A: It is a documentation of your cognition. It gives us a cognitive profile by which to make comparisons if cognition changes.

2. Why does talking about mood matter?

A: It is treatable with medications and talk therapy.

3. How do you differentiate depression from anxiety?

A: Both are treatable with medications and behavioral strategies.

4. What is apathy?

A: Apathy is a loss of interest in something you used to be very interested.

5. What do you do with people who don't want to take pills?

A: If you are taking or planning to take supplements, be sure to run them by your neurologist first.

6. What can be done with freezing?

A. There is a strategy used where you imagine a line on the floor and try to step over it. It has helped others.

7. If you are thinking about PD as a dopamine depletion disease, is there a way to stop it happening before it becomes a problem?

A: We know things happen before it is diagnosed. Some of these include complaints of constipation, loss of sense of smell, and sleep disorders.

8. What about family history?

A: There are patterns of Parkinsonism that runs in families. We have genetic testing

9. Are there programs for micrographica?

10. A: Speech therapist and occupational therapist treat this. There is a device: Pen Again that is a special writing instrument that you can find in some specialist stores or on the internet.

10. How does DBS work?

11. A: The treatment team targets where to place the electrodes very carefully. They use imaging and know exactly where to place the electrodes. It can often greatly reduce tremor.

11. What is the Hoehn-Yahr Scale?

A: It is a scale that describes 5 levels (stages) of severity of PD.

12. Is there evidence that depression and anxiety lead to PD?

A: We know that those with PD have chemical changes in the brain, as do people with depression. There is no evidence depression and anxiety lead to PD at this time, but we may learn more in the future.

13. Any comments on sleep?

A. It is important to have a regular schedule of sleep. Devices: TV, computers, cell phones, etc., can trick you brain into thinking night is day.

14. Does age matter for DBS?

A. The cut off is about 80 years of age, but there are exceptions.

President's Corner

With John Deck, Ph.D.

Dear Friends—This issue of the Newsletter includes the information shared at the Mini-Symposium, April 6, 2019 where Courtney B. Johnson, PH.D., and Mitch VanSumeron, Psy.D., of the Indiana University School of Medicine on the topic of Neuropsychology of Parkinson's Disease. We wish to thank them for their contribution to our further awareness of the cognitive changes that may occur with PD and how they may be managed.

On Saturday, July 27, 2019, PAACI partnered with the Davis Phinney Foundation, the Indiana Parkinson Foundation, and Rock Steady Boxing for the Victory Summit. We will cover some of the information from the Victory Summit in our next Newsletter.

Our annual PAACI Fall Symposium will be held on Saturday, September 14, 2019, at the Knights of Columbus located at 2100 E. 71st St. from 12 pm to 4 pm. Our featured speakers will be Dr. Lawrence Elmer, Director of the Parkinson's Disease and Movement Disorder Program and the University of Toledo Medical Center; and Jean Christophe (Chris) Rochet, PhD., professor of medicinal chemistry and molecular pharmacology at Purdue University. Be sure to read additional biographical information about these speakers in this information, and make a special effort to attend the Symposium. PAACI takes pride in providing very informative education programs as I am sure this will be one.

I wish to thank all of the board members of PAACI, and volunteers who have helped with the Davis Phinney Victory Summit, and a special thanks to the Davis Phinney Foundation for helping bring this special event to the Indianapolis community.

Directions to Symposium: 2100 E. 71st St., Indpls., IN 46220

From downtown Kokomo, IN:

53 Minutes, 42.5 Miles

1. Go West on W. Sycamore towards N. Buckeye St.
2. Take 2nd left onto S. Washington/IN-22.
3. Turn slight right onto S. Lafountain St./IN-931.
4. Turn slight right onto US Hwy 31 South.
5. Take Keystone Pkwy/exit 129B toward Rangeline Rd.
/Clay Terrace Blvd.
6. Keep left to Keystone Pkwy ramp. Turns into Keystone Ave.
7. Turn right onto east 71st St.

From downtown Avon, IN:

35 Minutes, 22.8 Miles

1. Go east on US Hwy 36 toward Park Place Blvd.
2. Go straight onto Rockville Rd. then merge onto I-465 North/USS Indianapolis Memorial Hwy North.
3. Take the 56th St. exit/Exit 19.
4. Turn slight right onto W. 56th St./Kessler Blvd. West Dr.
5. Kessler Blvd. West Dr. becomes Kessler Blvd East Dr.
6. Turn left onto E. Westfield Blvd./Broad Ripple Ave.
7. Left onto N. Evanston Ave.
8. Turn right onto E. 71st St.

From downtown Greenwood, IN:

38 Minutes, 23.6 Miles

1. Go east on W. Main St. toward Hwy 31
2. Merge onto 465 N toward Indianapolis.
3. Keep right to take I-70 East/exit 112A toward Columbus.
4. Take exit 85B toward Keystone Ave. N./Keystone Way.
5. Continue going straight to N. Keystone Ave.
6. Turn left onto E. 71st St.

From downtown Greenfield, IN:

36 Minutes, 26.9 Miles

1. Go north on N. State St./ IN 9 toward E. North St.
2. Turn slight left onto I-70 W ramp toward Indianapolis.
3. Merge onto I-465/US-31 N/US-52/US-421 via exit 90.
4. Take Shadeland Ave/56th St./exit 40.
5. Keep left to take Shadeland Ave ramp.
6. Merge onto N. Shadeland Ave.
7. Turn left onto E. 71st St.

Want to come to the Symposium, but need help?

If you'd like to come to this year's Parkinson's Symposium, but need a ride or help paying for your ticket please call the PAACI Office. PAACI is NOT supplying rides, but will post on our weekly e-blast that you're looking for a rideshare.

Also, Symposium grants are available to persons interested in coming to the Symposium, but unable to afford it. Also, if you would be interested in sponsoring someone else's Symposium ticket please include the additional donation with your Symposium and or dues payment and please mark it "Sym Tix Donation".

If you have any questions or need help with anything please contact Sheri at 317-255-1993 or sheripaaci@yahoo.com.

Fun! Fun! Fun at the Symposium

By Sheri at the PAACI Office

A few years ago Lisa Colleen Beale from Bongo Boys came to the fall Symposium and did a fun drum circle with all our attendees as part of the exercise break. Everyone had a great time, so I spoke with Lisa and she has agreed to come to the Symposium again this year. I hope you'll come and join us and have a great time!!!

Meet our Symposium Speakers

Lawrence Elmer, M.D., Ph.D.

Professor of Neurology

Director, The Center for Neurological Health

Director, Parkinson's Disease and Movement Disorders Program

Dr. Lawrence Elmer, Director of the Center for Neurological Health and Director of the Parkinson's Disease and Movement Disorder Program at the University of Toledo Medical Center will be providing us an update on diagnosis and treatment of Parkinson's disease.

He has been on their staff since 1998. He has been a lecturer on Movement Disorders for many years. He is considered an authority on Parkinson's disease, Parkinson's Plus

Syndromes, Dystonias, and has a strong interest in the area of molecular basis of neurodegeneration. He conducts research in these related areas and has also been honored with the award as one of America's Best Doctors.



Jean-Christophe (Chris) Rochet, Ph.D.



Jean-Christophe (Chris) Rochet, professor of medicinal chemistry and molecular pharmacology, is also the director of the Purdue Institute for Integrative Neuroscience.

An internationally recognized neuroscientist, Rochet specializes in studying central nervous system disorders, including Parkinson's disease, an age-related neurodegenerative disorder that disrupts the lives of an estimated 5 million people worldwide. His studies in models that reproduce key aspects of Parkinson's disease pathobiology have yielded new insights into genetic and chemical suppressors of neurodegeneration.

In 2018, research in Rochet's lab in collaboration with Riyi Shi, professor of basic medical sciences in the College of Veterinary Medicine, led to the discovery that the compound acrolein accumulates in Parkinson's disease-affected brain tissue -- a significant finding that could lead to new therapies as well as earlier diagnosis and prevention. In 2017, Rochet was part of an international team that found that a common asthma medicine could reduce the risk of Parkinson's disease by half. The research was selected as one of the top 10 drug discoveries of the year by the publication Technology Networks.

"Chris is highly accomplished in his field and has an impressive track record of international research, interdisciplinary collaborations and administrative leadership" says Tomás Díaz de la Rubia, vice president for Discovery Park. The Purdue Institute for Integrative Neuroscience, a part of Discovery Park, was founded in 2016 to leverage Purdue's strengths in science and engineering in several key research areas relevant to neuroscience, including neurodevelopment, neurodegeneration and neurotrauma, sensory systems, and neuroengineering.

Rochet obtained a PhD from the University of Alberta in biochemistry in 1998 and then worked as a postdoctoral fellow at Harvard Medical School, studying mechanisms of alpha-synuclein self-assembly in Parkinson's disease. He joined the faculty of Purdue University in 2002.

About Discovery Park

Discovery Park is a place where Purdue researchers move beyond traditional boundaries, collaborating across disciplines and with policymakers and business leaders to create solutions for a better world. Grand challenges of global health, global conflict and security, and those that lie at the nexus of sustainable energy, world food supply, water and the environment are the focus of researchers in Discovery Park. The translation of discovery to impact is integrated into the fabric of Discovery Park through entrepreneurship programs and partnerships.

About the Purdue Institute for Integrative Neuroscience

The Purdue Institute for Integrative Neuroscience is one of six interdisciplinary life science research centers harnessing the university's unique strengths to improve the quality of life for people around the globe. Through an ambitious integration of traditional life sciences with Purdue's powerhouse engineering program, PIIN aims to address the greatest challenges in mental illness and neurological disorders by revolutionizing diagnostic and treatment capabilities.

*** Information courtesy of Purdue University.

**Parkinson's Awareness Association of
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Facebook: Indianapolis Parkinson
Email: skauffman@paaci.org



Clip here

Dues, Memorials & Tulip Society Donations

_____ Today I would like to pay my annual PAACI dues of \$25.

_____ Today I would like to pay my Tulip Society donation of \$_____ (\$100 or more).

_____ Today I would like to make a donation in honor/memory (circle one) of a loved one.

Name of honoree: _____ Amount of donation: _____

Please mail acknowledgement of the donation to the family at: (Include name and address)

From: _____

Payments can be made by check to PAACI at P.O. Box 19575, Indpls., IN 46219 or by credit card on this form, by phone at 317-255-1993, or by the PAACI website at www.paaci.org and click on "Make a donation".

Name on card: _____ Phone: _____

Credit Card Number: _____ Expiration: _____

Zip code (where statements are received) _____ CVV Code: _____

Address: _____ City, State, Zip _____

Phone: _____ Email: _____

Signature: _____