

Indy PD Update

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

May-July 2018

Women's Conference on PD Stronger Together

With Dr. Maria De Leon

Saturday, July 28, 2018 (9am-4pm)
(Doors open at 8am)

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

Join us for an educational and inspirational conference on Parkinson's Disease. The conference is open to any woman with an interest in PD. Speakers are specialists in a variety of areas including movement disorders, care giving and clinical trials. You may even find yourself dancing or playing in a drum circle.

\$25 per person with a \$5 early bird discount until June 28, 2018.

See page 6 For registration.

Fall Parkinson's Symposium & Health Fair "Update on PD"

with Dr. Joanne Wojcieszek
& Jessica Huber, Ph.D.

Saturday, September 8, 2018 (1pm-5pm)

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

*****Special Price if Paid by 7/2/18***
\$10 per person for 2018 dues paying members**

\$20 per person for 2018 dues paying members

\$25 per non-dues paying members

**Annual PAACI
dues are just
\$25**

See page 7 For registration.

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Newsletter

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

Disclaimer: The contents or opinions expressed in this newsletter are those of the individual writers or presenters and do not constitute an endorsement or approval by PAACI Staff/Board. Please consult your personal physician, attorney or therapist regarding your individual medical or legal issues.

Please Pay your 2018 PAACI Dues

You can pay your annual PAACI dues by mailing a check to PAACI, P.O. Box 19575, Indpls., IN 46219, call Sheri at 317-255-1993 or go to www.paaci.org and hit the donate now button.

Upcoming Events:

1. **Women's Conference (July 28, 2018)**
2. **Annual Symposium (September 8, 2018)**
3. **Caregiver's Conference (November 10, 2018)**
4. **Holiday Party (December 1, 2018)**

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

Helpful Phone Numbers

PAACI Office—317-255-1993

American Parkinson's Disease Assoc.-800-223-2732
 Caregivers Spt Grp w/Catholic Charities—317-261-3378
 CICOA—317-254-5465
 Indiana Parkinson's Foundation & The Climb—317-550-5648
 Indiana Reading & Information Services—317-715-2004
 Parkinson's Foundation-1-800-473-4636
 Rock Steady Boxing—317-205-9198
 Shelby County PD Exercise & Support—317-398-7614
 (Currently limited to Shelby County residents and Major Health Partners patients)

Parkinson's Disease and the Management of Off Episodes

Presented by Cindy Zadikoff, M.D., MSc on April 28, 2018. Article written by John Deck, Ph.D.

Over one million people in the US have Parkinson's disease. There are approximately 60,000 Americans diagnosed annually. Worldwide there are 7 to 10 million individuals living with Parkinson's disease.

Parkinson's disease occurs when messaging is interrupted in an area of the brain that controls movement. What happens is that dopamine works in deeper areas of the brain, the cells degenerate, and this degeneration inhibits one's ability to move. The disease is "personalized." Every patient has different experiences, symptoms, and it progresses at different rates. Over time it becomes more difficult for the brain to control body movements. Common signs and symptoms of PD are:

1. Tremor: involuntary trembling of the limbs. However, 30% of those diagnosed do not have tremor.
2. Rigidity: muscle stiffness
3. Bradykinesia: Slowness starting and continuing movements or immobility
4. Postural instability: Impairment of balance and righting reflexes

Parkinson's treatment is also personalized. Levodopa/carbidopa is the most commonly used medication. Other medications include dopamine agonists (ropinirole, pramipexole, rotigotine, and apomorphine), MOA-B inhibitors (rasagiline, selegiline, and selegiline HCL), and COMT inhibitors (entacapone and tolcapone). Oral Parkinson's medications can be given in many combinations, most often with levodopa.

What are Off Episodes?

After taking levodopa for some time, you may find that it no longer provides consistent, reliable relief. A varying response may occur, and this is known as on time and off episodes.

On time is when during portions of the day, the oral levodopa medication is working well. Your symptoms are minimal, and you are moving and able to go about your daily activities.

Off episodes (off times): These are other times of the day when your oral levodopa medication is not working properly. Your symptoms re-emerge and are or near their worst; and you have difficulty moving, walking, and going about your day.

Types of off episodes may include:

1. Delayed on: When your levodopa medications take a while to start working.
2. Suboptimal on: When your levodopa medication sometimes provides partial relief.
3. Dose failure: When your levodopa medication fails to work at all.
4. End-of-dose wearing off: When it is almost time to take your next dose and your levodopa medication wears off too soon.

How do off episodes affect the patient?

Off episodes can last a few minutes up to a few hours. Some patients experience several off episodes a day and may result in limiting activities. Off times can interfere with work, time with family and friends, and limit daily living activities. The Michael J. Fox Foundation hosted an internet survey to demonstrate the daily impact of off times. Three thousand people with Parkinson's participated. The findings showed:

1. More than 90% said they had more than one off episode per day
 2. 65% reported being off for more than 2 hours per day.
 3. 50% said their episodes prevented them from performing activities that they can do when they are on.
-

How to keep on. By taking non-oral medications, like Apokyn, in the interim.

What is APOKYN (apomorphine hydrochloride injection)?

APOKYN is a prescription-only medication, used as needed to treat the symptoms of off episodes associated with advancing Parkinson's disease. It works by mimicking the activity of dopamine in the brain. It can provide a patient with the relief as their best response to levodopa. It can:

1. Provide rapid and reliable return to an on state.
2. Be used reliably first thing in the morning.
3. Help manage your PD symptoms by quickly ending off-episodes.
4. Help you walk, talk, and move around more easily.
5. Be used when you need it up to 5 times a day.
6. Start working as early as 10 minutes after the injection (most people feel relief after 20 minutes).
7. APOKYN lasts 60 to 90 minutes.
8. Can be added to almost any PD treatment regimen and can be used in addition to other oral PD medications.
9. It by-passes the stomach, so you do not need to alter meal times. APOKYN is not affected by GI problems that are posed by other oral medications.

A common type of off episodes is called "morning akinesia," which is when your first dose of levodopa may take 30 to 45 minutes longer to work; provides only partial symptom relief; or have no benefit at all (dose failure). Akinesia in the morning can be quite disabling as you want to "get things going."

APOKYN in clinical trials reversed 95% of off episodes, provided levodopa-like benefits in 90% of patients, and did not require increased dosing over time. It allows one to get back to your daily activities in 10 to 20 minutes. APOKYN is used by injection (just under the skin, not in a vein) to treat loss of control of body movements in people with advanced Parkinson's disease. It treats off episodes which may include muscle stiffness, slow movements, and difficulty starting movements.

Safety information includes:

1. Do not take APOKYN if you are being treated with certain drugs called 5HT3 antagonists (Anzement, Kyril, Zofran, Lotrones, and Aloxi) that are used for nausea, vomiting, or irritable bowel syndrome.
 2. Talk to your healthcare provider about adding APOKYN to your medication regime.
 3. Your healthcare provider might need to prescribe a medicine called Tigan (trimethobenzamide hydrochloride) to help prevent nausea and vomiting when you take this medication.
 4. APOKYN may cause sleepiness. One should not take a sleep aid when on this medication.
 5. APOKYN may lower blood pressure and cause dizziness and fainting.
 6. APOKYN may worsen cognitive and aggressive, impulsive behaviors.
 7. Individuals with PD have a greater risk of skin cancer (melanoma) and need to have this monitored.
 8. The most common side effects seen in clinical studies with APOKYN were yawning; sleepiness; sudden uncontrolled movements; dizziness; runny nose; nausea and vomiting; hallucinations; and swelling of hands, arms, legs and feet.
-

How to use APOKYN

1. APOKYN can be taken up to 5 times per day (small self-injection under the skin)
2. It uses a thin needle
3. Once trained you or your care partner may give the injection (usually in the stomach, upper thigh, or upper arm)

Who is an APOKYN candidate?

1. If your off episodes are not adequately controlled by your current medications
2. If you have trouble in the morning when your first wake up; have end of does wearing-off; your PD medications take too-long to work (delayed on); your PD medications fail to work; you have unpredictable off-times; if you are constantly timing your medications around your meals; and if you must schedule your daily activities around off-times.

Starting APOKYN

1. Your doctor needs to prescribe APOKYN, and may need to prescribe Tigan to help prevent nausea and vomiting.
2. APOKYN has a Circle of Care (CoC) program that is designed to assist patient and care partners in the use of APOKYN. The Circle of Care will maintain communication with you.
3. Get your prescription filled.
4. The initiation of your treatment will take place at your doctor's office or at your home as determined by your doctor.
5. You would continue in your prescribed program.

The Circle of Care is a program to assist you and your care partner in the use of APOKYN. It includes a Circle of Care Coordinator who will help you with insurance benefits, identifying a pharmacy, and locating financial assistance; Nursing Services including in-home visits, supportive phone calls, educational training, and ongoing support; and Home Medication Delivery, which includes specialty pharmacy providers who provide your prescription, refills, and will answer questions.

Questions and Answers:

Question: How do you define Advanced Parkinson's disease?

Dr. Zadikoff: Anybody who is having motor fluctuations on medication therapy, but it is not working optimally.

Question: How many times a day can you use APOKYN?

Dr. Zadikoff: Up to 5 times a day. It does not replace other medications. It bridges gaps.

Question: How much does it cost?

Answered by Nicole Henry, US World Meds Representative: \$25 to \$40 per month.

Thank you to our 2018 dues paying members:

(Tulip Society members listed on the back page have paid they're annual PAACI dues plus an additional substantial donation.)

Jeffrey & Barbara Bohard, Tina Brannon, Richard & Barbara Dudley, June Fisher, Catherine & Jerry Fuelling, Audrey Gentzke, John Gross & Rosemary Vania, Brian & Susan Henderson, Linda Hinkle, William & Gayle Howard, Thomas Irwin, Debra & Kevin Johnson, Kathy Krueger, Jeffrey Lax, Rosalba & Robert Mariacher, David & Nancy Martikke, Lee & Sally Peters, Helen Roleen Pickard, Tom Ransom, Randy & Diane Rowland, Mary Delaine Sans, Donald & Helen Schaefer, Virginia Shuman, Paula Slinger, Harry Sommer, William & Judy Summitt, Lon & Janice Tuin, Patsy Wilson, James & Susan Wolfe, and Dave Yeaman

Meet Joe and Sarah

On April 28, 2018 at the Mini-Symposium, Written by John Deck

At the April 28th Mini-symposium we had a testimonial from a couple Joe Possenthi, Jr., and Sarah Anello who live in Philadelphia. Joe, in his 50's was diagnosed with Parkinson's disease in 2009 but has likely had Parkinson's for 13 years; and Sarah is his care partner/girlfriend of 4 years, who grew up with an uncle who had PD for 30 years. Joe has a love for football and coaches high school football as well as has having a full-time consulting business managing local government. Sarah works at staging food network shows. This charming couple shared the awkward moments, and later humorous memories of their first dating. Dyskinesia and slurred speech on their first date: was he drunk? They are a couple who compliment each other. Joe expressed his appreciation of Sarah keeping after him to make sure his medications were working in the best way possible. He had difficulties with his medications turning on in the morning hours, and the APOKYN injection has made a big difference (as a bridge) in his getting his day started and doing his job. Joe takes APOKYN about 3 times per day. Joe commented that he can write his name legibly and reliably for the first time in years. They shared how diligently the Circle of Care program of APOKYN has worked for them, and complimented how important their Circle of Care Nurse, Leslie is to them. Joe summed things up by saying "If you laugh, you think, and you cry, that's a full day." This is a quoted of James Valvano, a noted basketball coach at North Carolina State University, who won the National Championship against the favored Houston Cougars in 1983. Mr. Valvano became a broadcaster later in his career, and he gave a memorable speech in 1993 using this quote and reminding his audience "to don't give up. Don't ever give." So just as Jim Valvano has been inspirational to Joe, let Joe be inspiring to us.

Women & PD Conference Registration Form

Registration is \$25 with a \$5 early bird discount until June 28, 2018. Lunch is included.

Name: _____

Street: _____

City: _____ State: _____ Zip Code: _____

Email: _____ Phone: _____

If paying by check, please make it payable to: PAACI.

If paying by credit card: circle one: Mastercard / Visa

Card Number: _____ Exp Date: _____

Name on Card: _____ 3-digit code: _____

Zip Code (where bill's sent): _____ Signature: _____

Please cut on the dotted line above and mail the registration form and payment to PAACI at PO Box 19575, Indpls., IN 46219. For credit card questions contact Sheri at 317-255-1993 or skauffman@paaci.org. For more questions regarding the program please contact Terri at 317-506-3666 or Paula at 317-408-0993.



**Parkinson's
Awareness
Association
Of Central
Indiana, Inc.
317-255-1993
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Parkinson's Symposium Registration Form

\$10 per person if 2018 dues & registration are paid by 7-2-18.

\$15 per 2018 dues paying member after 7-2-18.

\$20 per non dues paying member.

Dues: \$25 per household annually

<u>Name of Attendee:</u>	<u>Paying \$25 Annual Household Dues :</u>	<u>Amount Paying:</u>
Total Attendees:	Total Dues:	Total Payment:

Method of Payment: Check _____ Cash _____

Credit Card Payment (circle one): Mastercard Visa Expiration Date: _____

Credit Card Number: _____

Zip Code (where credit card statements are received): _____

Signature: _____

3 Digit code on the
back of card:

____ _

Contact Information

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

(Please include phone number for questions)

E-mail: _____

Please make checks payable to PAACI. Registrations and payments can be mailed to the PAACI Office at:

PAACI
P.O. Box 19575
Indpls., IN 46219

Contact Sheri at 317-255-1993 or e-mail
skauffman@paaci.org for questions or
more information

***Most time sensitive information is sent out through e-mail. 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 in the contact information.

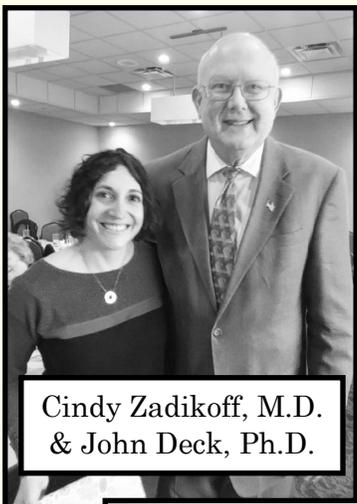
Pictures from the Mini-Symposium



Cindy Zadikoff, M.D. & Guest



Audience



Cindy Zadikoff, M.D. & John Deck, Ph.D.



Guest & Nicole Henry from US World Meds



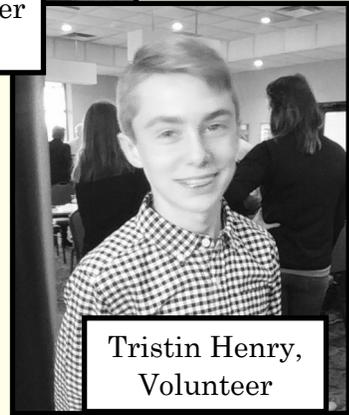
Sarah Annello, Joe Possenti, Jr. & Susan Szep



Guests with Bruce Gardner from Medtronics



Audience



Tristin Henry, Volunteer

The President's & Executive Secretary's Corner

.....with John & Sheri

We wish to thank all our members who attended our Mini-Symposium on Saturday, April 28th at MCL. Dr. Cindy Zadikoff, a Neurologist, from Northwestern University, spoke on 'Parkinson's Disease and the Management of Off Episodes.' Her presentation was very interesting and easy to understand (please see article on page 3). Joe Possenti, Jr., and Sarah Annelo a couple from Philadelphia also shared their experiences in the management of off- episodes and their testimonials were informative, and we enjoyed their fabulous sense of humor. We are grateful to all of them for their contributions and insight. We also wish to thank our sponsors of the mini-Symposium: Abbvie, Lundbeck, Medtronics, and US World Meds. A special shout out to those who contributed to the silent auction: Bokay Florist, Bravo Restaurant, Carmel Florist, Dairy Queen, Indiana Fever, Indianapolis Zoo & White River Gardens, Joann Whorwell, John Deck, Segway of Indiana, Sky Zone, Stephanie Combs-Miller, Sullivan's Hardware, Texas Roadhouse. We would also like to show our appreciation to the PAACI Board members: Joann Whorwell (who organized the silent auction) and Kathy Krueger, Dustin Arnheim, Stephanie Combs-Miller, Jeff Brodzeller, Rebecca Parks, and Terri Weymouth who helped in setting up and conducting the round table discussions. And one last big thanks to Tristin Henry, who helped up set up and move tables.

The roundtable discussions were held after the speakers were done. We asked our members in attendance to share their needs and comments about what we do well, and what we could do better, so that PAACI may better serve our Parkinson's community in the future. Some of the comments included people enjoying the Newsletter and E-blasts. We now invite those of you who could not attend to contact Sheri with your comments and/or suggestions at either 317-255-1993 or skauffman@paaci.org.

Since April was Parkinson's Awareness month, we want to thank you for joining us for the celebration. We appreciate those of you who paid your 2018 PAACI membership dues. We encourage those who have not paid their PAACI dues to consider paying them now. It is only with these contributions that we can we continue offering the Newsletter, Friday E-blasts, and educational programs and information to all of you. Please consider becoming a member of one of our donor categories which includes the PAACI dues and our Tulip Society memberships of Pink Tulip (\$100+), Orange Tulip (\$250+) or Purple Tulip (\$500+). Please note that Orange Tulip Society Members get half off all PAACI events and Purple Tulip Society Members get into all PAACI events at no charge.

PAACI Says Goodbye To Friends We've Lost:

Parke Brown
Lloyd Craig
Norma "Judy" Davids
Cirrie Ellis
Nelson Griffiths
James Klemm
Jim McGuire



John Kelsey
Clyde F. Ranney
Marilyn Ransom
Edwin & Marjorie Schulz
Ira "Wilson" Sherman
Douglas Wolfe
Janice Zapf

**Parkinson's Awareness Association of
Central Indiana, Inc. (PAACI)**

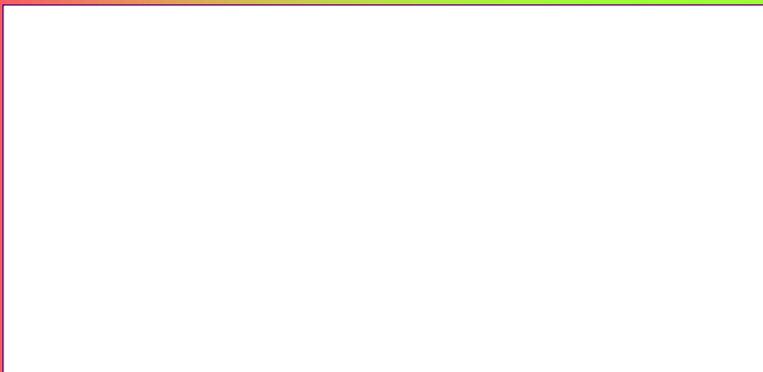
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317-255-1993

www.paaci.org

Facebook: Indianapolis Parkinson

Email: skauffman@paaci.org



Did You Know... that you, your business, your social group or your family can sponsor part or all of a PAACI Newsletter in honor or memory of someone special. Just contact Sheri at 317-255-1993 or skauffman@paaci.org for more details.

Tulip Society Members

(Tulip society membership includes PAACI dues.)

Pink Tulip Society Members

(Annual donation of \$100 or more)

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Joann Whorwell

Purple Tulip Society Members

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