

# Indy PD Update

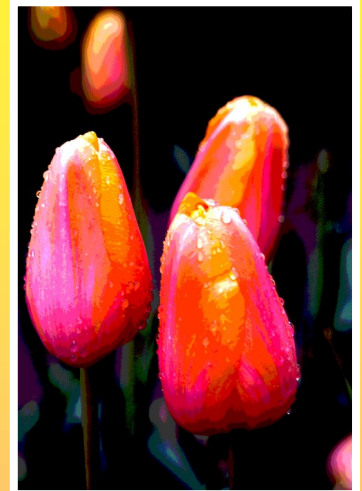
PRODUCED AND DISTRIBUTED BY: PAACI  
Parkinson's Awareness Association of Central Indiana, Inc.

February 2018– May 2018

## 2018 Parkinson's Mini-Symposium, Round Table Discussion & Silent Auction

Saturday, April 28, 2018 at 11 am

MCL Cafeteria at Township Line Rd.  
(2370 W. 86th St., Indpls., IN 46260)



Our keynote speaker this year will be Dr. Cindy Zadikoff. She will be discussing "Parkinson's Disease and the management of off episodes". This talk will be followed by a peer-to-peer discussion with Joe and Sarah, a Parkinson's patient and his long-term girlfriend (caregiver).

After the speakers, we invite you to join us for a round table discussion about what the Parkinson's community wants and needs. Please come and share with us the things that are important to you and your family and what you would like to see PAACI do in the future.



**This event is free and includes lunch.** Registration is requested. Donations would be appreciated and you can also pay your \$25 annual PAACI dues before or after lunch. We also hope that you'll peruse our silent auction items and bid on a few. Just remember all the money goes to a good cause.

Please see page 6 and 7 for more details and registration information or contact Sheri at 317-255-1993 or [sheripaaci@yahoo.com](mailto:sheripaaci@yahoo.com).

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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 [skaffman@paaci.org](mailto:skaffman@paaci.org) and put Friday E-blast in the topic line or call Sheri at 317-255-1993.

### **PAACI Board Members**

John Deck—**President**  
Jeff Brodzeller—**Treasurer**

**Members at Large**—Rebecca Parks, NP; Edward Daly, M.D., Ph.D., Stephanie Combs-Miller, Joann Whorwell, Dustin Arnheim, Kathleen Krueger, Linda Hinkle and Terri Weymouth

**PAACI Executive Secretary**—  
Sheri Kauffman

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### **Newsletter**

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

**Funded by** your donations and the Parkinson's Awareness Association of Central Indiana, Inc.

**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)

# Income Tax Benefit of the IRA Charitable Rollover

## By Jeffery D. Stinson, CELA\*

Recent changes to income tax law may result in fewer individuals taking advantage of the traditional charitable deduction, but individuals can still receive a reduction in income tax by using their Individual Retirement Account (“IRA”) when completing charitable goals.

### The Change

The Tax Cuts and Jobs Act was signed into law last December (2017). The new law, among a myriad of other tax code changes, effectively doubled the standard deduction for single filers and joint filers. The Tax Policy Center of the Urban Institute and Brookings Institution has estimated that 75 percent fewer taxpayers will itemize deductions with the increased standard deduction. The charitable deduction is part of the itemized deductions. So, many taxpayers will no longer receive a charitable deduction unless they increase their charitable gifts.



### The IRA Charitable Rollover

The IRA Charitable rollover allows owners of a Traditional IRA (or inherited Traditional IRA) who are age 70 ½ or older to make tax-free IRA contributions directly to qualified public charities. Each age-eligible IRA owner can transfer up to \$100,000 tax-free per tax year. The IRA gift must be made on or before December 31 of the calendar year in which the taxpayer wishes to use the IRA Charitable Rollover gift vehicle for income tax purposes. The check from the IRA must be made out directly to a charity, not the IRA owner.

### Advantages of IRA Charitable Rollover

Once a taxpayer turns 70 ½, the taxpayer must start taking “required minimum distributions” out of the taxpayer’s traditional IRA. The required minimum distribution is typically taxable income to the taxpayer. However, if the taxpayer utilizes the IRA Charitable Rollover, the amount given to the charity counts as part of the taxpayer’s required minimum distribution, but is not taxable income to the taxpayer. **This is a big benefit, especially if the taxpayer does not itemize deductions.**

Even for taxpayers who do itemize, the IRA Charitable Rollover can still save the taxpayer more tax than taking the IRA distribution into income and then donating it. For example, by donating IRA funds directly to the charity from the IRA, the taxpayer lowers adjusted gross income. This, in turn, may keep other income from being subject to the 3.8% net investment income tax. It can also eliminate high-income premium surcharges for Medicare.

For taxpayers who must take a required minimum distributions and do not itemize, the IRA Charitable Rollover is a no brainer. It will reduce tax for charitable gifts in which the taxpayer may not otherwise receive an income tax advantage. For taxpayers who itemize, the IRA Charitable Rollover can still be of benefit as cited above. The transfer process to complete an IRA Charitable Rollover is quick and requires minimal paperwork. The key is to ensure that the check from the IRA is made out to the charity. Contact your tax preparer or attorney to see how the IRA Charitable Rollover may benefit you.

*\*Certified as an Elder Law Attorney (CELA) by the National Elder Law Foundation*

*Information and articles are presented as a public service by the Stinson Law Firm, LLC. We help our clients protect their assets and access long-term care assistance. This article is general in nature and is not to be taken as legal advice to any particular person. Consult an attorney for specific legal advice for your circumstance.*

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# Genetics and Parkinson's Disease

With Alexe' Engel, B.A., B.S.—Written by John Deck



Alexe' is pursuing her M.D, Ph.D at IUPUI. She is in her second year of medical school, and her third year of graduate school. She is studying Parkinson's disease from a structural biologist's perspective. She is studying the structure of proteins. If you know the structure of the proteins you hope to understand why their functions have changed when they have mutated, causing Parkinson's disease. The hope is to design a drug to modulate the structure and thus the function, and to prevent the progression of the disease, and possibly reverse it. Parkinson's disease is associated with the protein PINK 1.

By 2050, there will be a dramatic increase in the world's population of those who are over 50 years of age. The prevalence of PD will increase due to the dramatic improvement in life expectancy. In the early 1800's, when James Parkinson first described the disease, life expectancy was 40 years of age. In 2017, 200 years later, life expectancy has increased to 80 years of age. The risk of developing Parkinson's disease increases greatly after age 65.

Parkinson's disease is a progressive disease with symptoms of resting tremor, bradykinesia, rigidity, and postural instability. PD is the result of selective cell death of the dopamine producing neurons in the substantia nigra.

There are two forms of PD: the sporadic form (of unknown cause), which accounts for 80 to 95% of the cases; and the familial form (genetically transmitted), accounting for 10 to 15% of the cases. Research is finding links between the two forms.

Mitochondrial dysfunction is the loss of efficiency in the electron transport chain and reduces the synthesis of high-energy molecules in neural function. Mitochondrial dysfunction had been suggested to be involved in the biological mechanism of the familial form initially, but now so has the sporadic form of Parkinson's disease. Mitochondria are structures in cells that regulate cell energy well-being, and also cell death. Damaged mitochondria are removed through autophagy (an orderly degradation and recycling of cell components). This process relates to neurodegenerative diseases including Parkinson's disease. Alexe' is studying the PTEN Induced Kinase 1 (PINK1), as it may be a signaling pathway. It transfers phosphate groups via electron transport particles to another protein. It helps maintain mitochondrial integrity and may be protective while helping to recycle the mitochondrial.

She presented a model of Parkin-Induced Mitophagy. PINK 1 recruit autophagy receptors, which allow the orderly degradation and recycling of cellular component, are used to induce mitophagy (the process of degrading and recycling cellular components). There is hope we will learn more about the process and be able to use this information to develop therapeutics. By determining the structure of PINK1, we hope to isolate which interactions are responsible for the effects associated with the disease. By breaking down the parts of the protein to study we will hopefully determine which parts are conserved and which parts have mutated, thus being able to move ahead with therapeutic interventions.

Bioinformatics uses methods to predict protein structure using amino acids to predict secondary structures. Tertiary protein structure analysis is used to observe folds (a cellular stress response) of the structure. Mass spectrometry is used also in the study.

## **The steps of the analysis include:**

1. Isolation of the protein;
2. Purification of the protein;
3. Protein analysis. By looking at the kinase activity (a protein that is part of cellular activation) and purification we can correlate the abnormal activity to the structures in hope of finding molecules to stabilize the mutation.

# Genetics & PD Questions and Answers:

**1. How will this research make a difference?**

a. *PD was originally characterized by the symptoms. Now we know we can find proteins that have mutated to cause PD. We can find other proteins along the molecular pathway and hope to modify them.*

**2. How do you find mutated proteins?**

a. *Using DNA samples and individualized mutations.*

**3. Does Parkinson's have other causes?**

a. *The risk of the disease can be amplified by environmental risk factors.*

**4. Are there some bacterial indications for PD?**

a. *There is some evidence for both bacterial causes and mutations.*

## Jeff Brodzeller Honored as Connie Carney Award Recipient



John Deck, Rebecca Parks, Jeff Brodzeller & Tammy Brodzeller (Left to right)

The Connie Carney Memorial Award is in honor of an astounding woman who lived her life graciously with

Parkinson's disease while donating a significant amount of her time to the Parkinson's Awareness Association of Central Indiana, Inc. (PAACI) and the local Parkinson's Community. In honor of all that Connie Carney did in the name of PAACI we have established an annual award to honor and celebrate a person who has given of themselves to PAACI and the Parkinson's Community in a gracious and loving manner.

In 2017, the PAACI Board elected as the honoree of the Connie Carney Award, Jeff Brodzeller. Jeff has been living with Parkinson's for more than 15 years and a few years ago had the deep brain stimulation implanted. Jeff has also served on the PAACI Board for many years. He's been PAACI's Treasurer for most of that time and he's also served as President. Jeff has been an amazing and consistent asset to PAACI. You can see his smiling face at so many PAACI's events and he's always willing to lend a helping hand whenever it's needed. Jeff had also served as the treasurer on the board of the Young Parkinson's of Indiana support group. We are truly lucky that we've had the devoted service and support of Jeff and his family all these years. We are pleased to honor Jeff Brodzeller with the Connie Carney Award.

Women & PD Conference Coming Soon...

Please mark your calendar for the Women & PD conference coming up on Saturday, July 28, 2018.

## **Parkinson's Mini-Symposium Speaker & Roundtable discussion**



**Cindy Zadikoff, MD, MSc**  
Northwestern University  
Department of Neurology  
Parkinson's Disease and Movement Disorders Center  
Associate Professor of Neurology  
(Movement Disorders) and Medical Education

Dr. Zadikoff's clinical and research interests include: therapeutic treatments for advanced Parkinson's disease, deep brain stimulation for the treatment of movement disorders, and management of Atypical Parkinsonian Syndromes and other movement disorders including essential tremor and chorea; Botulinum toxin injections for the treatment of dystonia, Lewy Body Dementia, Progressive Supranuclear Palsy, and advancing the understanding and treatment of functional movement disorders.

Dr Zadikoff has contributed to more than sixty publications with her most current being :

“Pedunculopontine nucleus stimulation in progressive supranuclear palsy: A randomized trial” in the Journal of Neurology, Neurosurgery and Psychiatry.

“National Randomized Controlled Trial of Virtual House Calls for People with Parkinson's Disease: Interest and Barriers” in Telemedicine and e-Health.

“Integrated safety of levodopa-carbidopa intestinal gel from prospective clinical trials” in the US National Library of medicine National Institutes of Health.

Dr. Zadikoff currently leads the following active clinical trials that are recruiting research participants/patients including:

-A Phase 3 Study to Examine the Efficacy, Safety and Tolerability of APL-130277 for the Acute Treatment of OFF Episodes in Patients with Parkinson's Disease

-Safety and Efficacy Study of Tozadenant to treat End of Dose Wearing Off in Parkinson's Patients Using Levodopa

-RESTORE: A clinical study of patients with symptomatic neurogenic orthostatic hypotension to assess sustained effects of dRoxidopa therapy.

### **Meet Joe & Sarah**

Joe is a 52 year old from Aston, PA who was diagnosed with PD in 2009.

Joe, an avid football fan and accountant, approaches managing and treating his PD with preparation, toughness, focus, the support of a great team and a healthy dose of humor.

Joe lived with what he thought were old football injury symptoms for three years, until an old friend asked if he'd had a stroke—this ultimately led Joe to a diagnosis of PD.



Sarah is Joe's very beautiful and proactive long-term girlfriend. It wasn't long after they started dating that she noticed the all too familiar signs of PD—slurred speech, dyskinesia, and uncontrolled movements. Sarah had watched her uncle suffer from similar symptoms and knew PD didn't have to be a death sentence. She watched her uncle improve after taking advantage of different PD treatments and was determined to prove to Joe that he could too.

## The President's Corner... With John Deck

Hello Friends-

This issue of the Newsletter includes the second segment of information from the 2017 Symposium: Alexe' Engel's presentation on Genetics and Parkinson's disease. I had to do a bit of reading about structural biology to help write this and found this new direction of "precision medicine" (a way of looking at a disease model's molecular driven subtype) to be very interesting. I wish to personally thank our speakers Dr. Alberto Espay (Debunking Major Myths in the Treatment of Parkinson's disease); Brenda Kenyon, MSW, (Using Music to Improve Your Health); and Alexe' Engel for helping make our

Symposium such a success. (If you'd like our last Newsletter with the other Symposium articles please call Sheri at 317-255-1993.) I wish to also thank our many sponsors and volunteers, and a special thank you to our youth volunteers Tristan Henry and Nicholas Bowman (our photographer) for helping. Sheri Kauffman did a splendid job in helping plan this event and Joann Whorwell did an impressive job organizing the silent auction.

I also wish to express my appreciation to those of you who attended the Holiday Party at MCL on Dec. 8. Unfortunately Mother Nature wasn't kind that day, and we wish more of you could have attended. I would also like to again thank Joann Whorwell for organizing another fun silent auction.

Sheri is informing us in this Newsletter of PAACI's plans for the upcoming Mini-Symposium to be held Saturday, April 28<sup>th</sup>. For more information turn to page 6. So, mark your calendar and plan to attend and help us celebrate April as Parkinson's Awareness month.

I also want you to know that since PAACI is governed by a board of directors, we held election of officers in December of 2017 and I'm pleased to announce that our current list of officers is:

President: John Deck

Vice-president of Communications: Dustin Arnheim

Vice-president of Development: Dustin Arnheim

Co-vice presidents of Programs: Linda Hinkle and Terri Weymouth

Vice-president of Publications: Stephanie Combs-Miller

Treasurer: Jeff Brodzeller

Executive Secretary: Sheri Kauffman

Thank you for volunteering to serve in these elected positions.

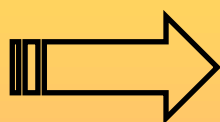
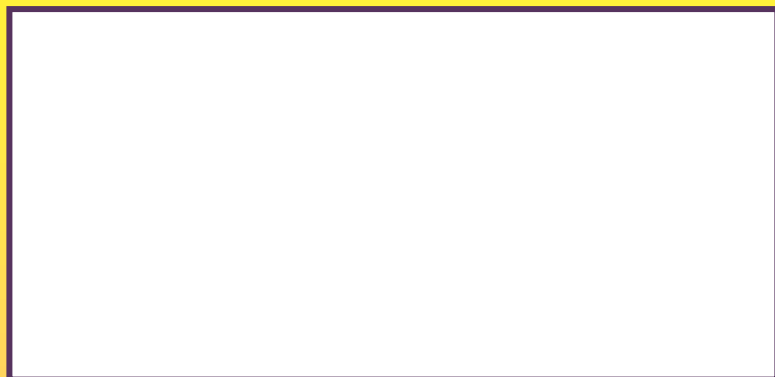
At our board meeting on Saturday, January 27<sup>th</sup>, we began setting new goals. At our Saturday, April 28<sup>th</sup>, Mini - Symposium we plan to conduct Roundtable discussions for our membership to speak up and share their needs and comments so we may better consider them in our future planning.

We are entering a new year, 2018. PAACI relies on our membership to pay dues, make donations, memorial contributions, grants and sponsorships for our scheduled events and operations. We greatly appreciate your support! Please consider being a dues paying member and/or renewing your dues at this time. These donations allow us to produce our quarterly Newsletter, maintain our webpage, send weekly e-blasts, maintain phone contact and mail information to those who contact us seeking answers to questions they have about Parkinson's disease and caregiving. We also have donor levels of our Tulip Society that include the Pink Tulip (\$100-\$250 annual donation), Orange Tulip (\$250-\$499 annual donation) and the Purple Tulip Society (\$500+ annual donation). Please consider honoring us with a pledge.

You can find us on Facebook at Parkinson's Awareness Association of Central Indiana – PAACI. Our website is [www.paaci.org](http://www.paaci.org) and if you'd like to get added to our Newsletter or Friday E-blast list just send an email to Sheri at [skauffman@paaci.org](mailto:skauffman@paaci.org).

We hope to see you Saturday, April 28<sup>th</sup>.

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



Clip here

## **Dues, Donations and Tulip Society**

\_\_\_\_\_ Yes, I'd like to pay my \$25 2018 PAACI dues. I know this helps PAACI and will also give me a discount to all PAACI events.

\_\_\_\_\_ Yes, I'd like to become a member of the Tulip Society. I'll pay \$\_\_\_\_\_ to become a member of the Tulip Society and help sponsor the PAACI Newsletter. I know that a \$100 or more donation will make me a Pink Member, \$250 or more will make me an Orange Member (with half price tickets to all PAACI events), or \$500 or more will make me a Purple Member (with FREE tickets to all PAACI events).

\_\_\_\_\_ Today I would like to make a donation in honor or memory of a loved one.

Name of honoree: \_\_\_\_\_ Amount of donation: \_\_\_\_\_

***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](http://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: \_\_\_\_\_