

# Indy PD Update

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

Jan. 2020 - March 2020

## Upcoming Parkinson's Events:

As we're starting 2020, we are planning our educational events for this year. So, below you will find a list of our upcoming events. Please put them on your calendar. Please look for more information coming in this Newsletter and in the Friday e-blasts. If you're not currently getting the Friday e-blasts and would like to please contact Sheri at 317-255-1993 or by e-mail at [sheripaaci@yahoo.com](mailto:sheripaaci@yahoo.com).

**Saturday, March 14, 2020 at 2 pm**

**Spring Tea for PD—FUNdraiser for PAACI**

at Serenity—135 S. Main St., Zionsville, 46077

Spring Salad, Tea Sandwiches, Mini Quiche, Scone,  
Clotted Cream, Sweets & Tea

\$25 per adult

Contact—Sheri 317-255-1993 or [sheripaaci@yahoo.com](mailto:sheripaaci@yahoo.com)

**Saturday, April 18, 2020**

Spring Parkinson's Symposium

Sponsored by PAACI, the Parkinson's Foundation and  
The Indianapolis Center for Excellence

**Saturday, July 18, 2020**

Women and Parkinson's Conference

**Saturday, September 12, 2020**

Fall Parkinson's Symposium

**November, 2020 (date to be announced)**

CareCon Caregiver Conference

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

### **PAACI Board Members**

**President**—John Deck

**Treasurer**—Jeff Brodzeller

**VP of Programs**—Terri Weymouth

**Unofficial VP of Silent Auctions**—

Joann Whorwell

**Members at Large**—Rebecca Parks, NP;  
Edward Daly, M.D., Ph.D., Kathleen Krueger

**PAACI Executive Secretary**—

Sheri Kauffman

### **Newsletter**

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

**Funded by** your donations (including dues & Tulip Society Memberships) and the Parkinson's Awareness Association of Central Indiana, Inc.

**Arranged & Edited by** Sheri Kauffman & John Deck

### **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

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

# Clinical Update on Parkinson's Disease 2019

By: Dr. Lawrence Elmer, Professor of Neurology

As written by: John Deck, Ph.D.



Dr. Elmer reflected upon how he had spoken at the PAACI symposium in 2011 and was happy to return. He said that things have changed in the past 8 years. He then showed a few short videos of Parkinson's motor symptoms and quoted writings from Dr. James Parkinson's circa 1817:

Shaking Palsy: "Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported, with a propensity to bend the trunk forwards, and to pass from a walking to a running pace the senses and intellect being uninjured. "There appears to be sufficient reason for hoping that some remedial process may ere long be discovered, by which, at least, the progress of the disease may be stopped." That was said more than 200 years ago.

Back to the present. There are common treatment issues. The symptoms include: stooped posture, small handwriting, decreased arm swing, changes in facial expression, tremor and shuffling walk. Bradykinesia is also very prevalent and is described as difficulty in initiating and maintaining movement. Rigidity is also present 95% of the time. Unfortunately, there is no cookie cutter approach to diagnosing or managing PD.

## **Breakthroughs in Pathogenesis (understanding how the disease begins and progresses)**

In the 1990's Dr. Heiko Braak, from Germany, described a mutation in the alpha synuclein gene identified in families with Parkinson's disease. We also know there is aggregation (or clustering) of alpha synuclein in Lewy Bodies of sporadic Parkinson's disease and dementia with Lewy bodies. We know that pesticides and herbicides are environmental risk factors. We think that exposure to toxins in the environment (inhaled or swallowed) affect nerve cells, and then it moves from one nerve cells to the other. It may take 10, 15, or 20 years for it to migrate to the substantia nigra. This is the foundation of the Braak hypothesis. It also spreads to the autonomic nervous system and damages that. Normally as we age the autonomic nervous system is more challenged.

Genetic causes of Parkinson's are rare. We think there is a genetic susceptibility in families, but it is likely the disease is environmentally triggered.

Challenging treatment issues may also include: falling, freezing, orthostatic hypotension, sleep disturbances, dementia, psychosis, sexual and bladder dysfunction, and others. Premotor diagnosis of PD may include constipation, depression, anxiety, low blood pressure on standing, light headedness, fatigue, apathy, pain, slowed thinking, memory difficulty, urinary problems, sexual problems, reduced sense of smell, and sleep disturbances.

## **Treating Parkinson's Disease**

Since the 1960's there have been advances in every decade with new and improved medications. Whereas in the 1960's we had levodopa, amantadine, and anti-cholinergics, by the 1990's we had added carbidopa, benserazide, selegiline, dopamine agonists (bromocriptine, and pergolide). And by 2000 tolcapone, entacapone, and the dopamine agonists pramipexole, ropinirole, and baclofen. In 2019, we have orally dissolving carbidopa/levodopa, zydys selegiline, dopamine agonists (apomorphine, ropinirole XL, and rotigotine).

There are many drugs under development including levodopa formulations: CVT-301 (Acorda), Acordin pill, Dopafuse, and NDO612L (pump-patch).

Other dopamine agonists being developed are the apomorphine infusion, and the apomorphine sublingual film. Other developments are Dipragluan IR, AVP-923 dextromethorphan/guanidine, Elloprazine, AQW052 Calpha nicotinic receptor, and nicotinic receptor agonists.

Neuroprotective agonists on the development list include: Inosine, Isradipine, Nicotine NAC, Nicotina, monoclonal antibodies to misfold alpha-synuclein, and affitope PDOIA vaccine.

Deep brain stimulation was approved for use with Parkinson's in January 2002, and can be very beneficial.

### **How do we stop Parkinson's?**

There is a need for pre-motor diagnosis.

We know that 90% of PD patients present with hyposmia (reduced ability to smell), making it arguable that in addition to tremor, rigidity, bradykinesia, and postural instability hyposmia should be a cardinal symptom of PD. Studies indicate that many patients develop hyposmia more than 5 years prior to the onset of the movement disorder. This also means that the majority of patients with an idiopathic hyposmia who do not develop PD 5 years after the appearance of it may be safe. Gastrointestinal disturbances are common in PD and may precede the occurrence of motor symptoms.

There is a large study called "Parkinson's Progression Markers Initiative, (PPMI). The landmark PPMI study is amassing the most robust Parkinson's dataset and biosample library in the history of Parkinson's research, leading to scientific discovery and biomarker validation. PPMI is also a cornerstone for collaboration and a model for trial design. We know if you have REM Sleep behavior disorder you are more likely to develop PD. This can occur 5 to 10 years before the Parkinson's is diagnosed.

### **What about Vaccines?**

Affitope PDO1A is being tested as a potential Parkinson's vaccine. This is an antibody against alpha synuclein. The companies Biogen, AstraZeneca and Tkeka, as well as Proclara are testing alpha synuclein antibodies.

### **What about inflammation in Parkinson's disease?**

There is inflammation in Parkinson's disease. Once the disease starts inflammation occurs, and this damages other cells. Studies are being done with monoclonal antibodies (they target specific areas of the brain) to reverse the inflammation.

### **Gene and Stem Cell Therapy**

There is a study with man-made stem cells, and there are a couple of studies with gene therapy.

In closing Dr. Elmer said the Movement Disorder doctors want you to be as close to normal as possible.

He commended the Michael J. Fox Foundation for the great work they have done in promoting research.

### **Questions and Answers.**

1. Is there anything that can help the autonomic nervous system?
  2. A: Previously you had to have a group of symptoms to be diagnosed with orthostatic hypotension. We now have Droxidopa to treat orthostasis. Having low blood pressure can cause orthostasis. Try eating a little more salt. Your symptoms can be erratic. Sleep on a wedge pillow, as the angle keeps the autonomic nervous system working. Snack on potato chips before you get up. The autonomic nervous system has a mind of its own.
2. What about the keto genetic diet?
 

A: We know amino acids (which are made of protein) can block the action of levodopa. You must be careful when you eat your protein. Cheese has protein and fats. Fats slow down the rate of digestion and block the levodopa longer. Eat high protein items, like cheese, and peanut butter closer to bedtime so you do not suffer the levodopa blocking side effects so much.
3. What about the gut?
 

A: The vagus nerve connects the gut to the brain. We do not know what bacteria may be contributing to the cause of the inflammation. Microglial and astrocyte cells in the brain are the ones that become inflamed.



## The Search for Disease Modifying Therapies in Parkinson's Disease

By Chris Rochet, Ph.D., Professor of Medicinal Chemistry and Molecular Pharmacology,  
Director of the Purdue Institute for Integrative Neuroscience  
As written by John Deck, Ph.D.

Dr. Rochet shared he has been interested in Parkinson's Disease research since his post-doctorate research days at Harvard. He feels Parkinson's research is very exciting. Dr. Rochet is the director of the Purdue Institute for Integrated Science. Parkinson's is one of the major areas of their interest and research.

There are symptomatic therapies for PD, but no treatment to slow the progression of the disease. His research is focused on slowing the progression.

Neurodegenerative diseases are more often in the news. He shared slides of famous people who have or had PD, including Pope John Paul, Michael J. Fox, Mohammad Ali, Neil Diamond, and others. Parkinson's disease was first described by James Parkinson in 1817. It is a major cause of disability in patients over the age of 60 and affects 5% of the population over the age of 85. More than one million Americans are affected, and more than 5 million people worldwide. In 2010, the annual cost of PD was reported to be greater than \$14 billion in the U.S.

### **History**

PD is a chronic, progressive, irreversible disease. He shared the abbreviation of the symptoms "TRAP":

**T**remor, at least primarily on one side of the body.

**R**igidity (muscular stiffness)

**A**kinesia/bradykinesia (slow movement)

**P**ostural instability (impaired balance)

PD is not just a motor disorder. Memory and other cognitive difficulties may be present.

PD is characterized by a loss of dopamine neurons in the substantia nigra. Dopamine neurons in the substantia nigra project to the striatum, and PD involves a loss of neurotransmission through the nigrostriatal system. Surviving neurons in the brain of PD patients have protein deposits called Lewy bodies that contain clusters (aggregates) of the protein alpha synuclein. By the time the earliest symptoms present themselves, already 50% or more of the substantia nigra cells producing dopamine, are lost. There is a spreading of the Lewy body pathology during the course of the disease.

Patients with early onset have a mutation in the genetic coding of the alpha synuclein. Mutant forms of the alpha synuclein can cause familial PD.

Another clue about the cause of PD is that environmental poisons inhibit the transmission complex. Examples of poisons include pesticides (rotenone), herbicides, metals (manganese) and MPTP (a heroin contaminant).

### **How does alpha synuclein cause neurotoxicity?**

Alpha synuclein controls the neuronal firing by regulating the fusion of vesicles to the synaptic membrane. There is genetic evidence that alpha synuclein is the major component in Lewy body disease. Dr. Rochet gave examples of this very complicated process, including that mitochondria are energy producers in the cells and how the alpha synuclein diminishes the dopamine. This research is in evolving stages in the lab and with animal research.

Rats injected with a virus (A53-E, a virus having alpha synuclein) showed evidence of motor asymmetry and neurodegeneration.

A second research strategy looks at peptides and how they interfere with alpha synuclein aggregation in the presence of lipids. Researchers are seeking strategies to slow the degeneration. They hope to develop inhibitors that will react at the membrane of the cells and prevent neurotoxicity.

## Neuroprotective effects of blueberries and other botanicals

There are neuroprotective effects that can be enhanced by diet. Epidemiological data suggest that the consumption of fruits enriched with anthocyanins is associated with a lower risk of PD. Blueberry (BB) and elderflower extracts interfere with neuron death caused by rotenone.

### In Summary

1. Alpha synuclein formation on the membranes and alpha synuclein mediated vesicle disruption may play key roles in neuron death in PD.
2. Peptides that interfere with membrane induced alpha synuclein aggregate formation are powerful tools to investigate the mechanism of alpha synuclein toxicity in animal models and PD. Hopefully they may lead to new therapies.
3. Botanical extracts revealed by epidemiological or ethnopharmacological studies have neuroprotective effects that could be considered to lower the risk of PD.

### Questions and Answers:

**Q: What poisons in the environment should be considered a PD risk?**

A: Manganese is what you are talking about. The site of entry could be the gut or the olfactory system.

**Q: Where are the clinics at Purdue? Do you need human subject participants?**

A: He suggested you contact Dr. Jessica Huber, about the need for subjects. You can reach her at 765-494-3796 or [jhuber@purdue.edu](mailto:jhuber@purdue.edu)

**Q: How many blueberries should you consume?**

A: He said it would be high, as in several pints a day, and that is because they must pass through the blood- brain -barrier.

**R: Q: Is there anything on the horizon?**

A: I am encouraged. The disease is more complicated than we previously thought. The technology has advanced, and we are getting closer to understanding the disease. We are closer to biomarker analysis which will allow earlier diagnosis. Advances in our research treatment will likely change in the future and be more neuroprotective.

## Connie Carney Award

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.

We are pleased to announce that Dr. Joanne Wojcieszek the 2019 Connie Carney Award Recipient. We offer our congratulations for this honor.

Dr. Joanne Wojcieszek is Clinical Associate Professor of Neurology, Indiana University School of Medicine and Director of the Movement Disorder Clinic, Indiana University School of Medicine, and a senior member of the neurology staff at the Huntington's Disorder Clinic. She has been an avid supporter and provider of services to the Parkinson's community and promoter of PAACI for more than 20 years. On numerous occasions she has been the keynote speaker at the PAACI annual Symposium has been an invaluable resource of assisting us in recruiting nationally recognized speakers for our educational events, and has advocated the importance of Parkinson's support groups throughout the state of Indiana. She had the honor of being nominated by the late Senator Richard Lugar to be a "Local Legend."

Dr. Joanne joins the ranks of previous recipients: 2018, Ed Daly; 2017, Jeff Brodzeller; 2016, the Pressner Family; 2015, Paula Tomlin; 2014, Eric Siemers; 2013, Rebecca Parks; 2012, Julie Sanderson; and 2011, John Deck.





## The President's and Executive Secretary's Corner with John Deck & Sheri Kauffman

In 2019 we stayed pretty busy. We offered our members a Mini-Symposium, Symposium, Caregiver Conference, two Tea Parties, a Holiday Party, and we co-partnered with Davis Phinney on the Victory Summit with the Indiana Parkinson's Foundation and Rock Steady Boxing. We hope that you were able to join us for some, if not all of these events.

We had great speakers that included Dr. Lawrence Elmer, Jean-Christopher Rochet, Ph.D., Maryann Abendroth and Lisa Colleen from Bongo Boy RMC. We also had some amazing

sponsors that included US World Meds, Medtronic, The Voice Clinic, Abbvie, Boston Scientific, Lundbeck, Acorda Therapeutics, Abbott, Acadia, Amneal, Stinson Elder Law, American Senior Communities, Senior Health Insurance Assistance Program, and Prestige Performance II. We also had many wonderful volunteers that made all of this happen. Special thanks to Joann Whorwell who is the "Queen of Silent Auctions". She did an amazing job this year, as she always does.

Thanks to all the businesses that have donated items or gift cards for the silent auctions. These businesses include: Abuelo'sm, Altum's, Bokay Flowers, Bravo, Charleston's, Colt's Football, Conner Prairie, Conrad Indianapolis, Dance Kaleidoscope, Dark Armies, Dr. Zygmunt, Eiteljorg Museum, Gilberts Flower Shop, Handel's Ice Cream, Indianapolis Indians, Indianapolis Zoo, Joann Whorwell, John Deck, Johnny Carino's, Main Event, MCL Restaurant, Olive Garden, Outback Steakhouse, Pacers Basketball, Panera Bread, Segway of Indiana, Sky Zone, Stacked Pickle, Starbucks, Stonecreek, Sullivan Hardware & Garden, Texas Roadhouse, The Melting Pot, Tried & True Alehouse, Wheel fun Rentals, and the Women's Prison Community Outreach.

We would also like to take a minute to thank all of our donors who include our dues paying members, our Tulip Society Members and our memorial/honorarium donors, who took the time to honor their loved ones both alive and in passing. And last, but certainly not least, we want to give our greatest thankfulness to those who honored PAACI by remembering us in their final wishes, and included us in their will with a bequest.

Now, for 2020. We hope to make this another wonderful year. We are currently in the process of planning this year's events which will include a joint Spring Symposium on April 18<sup>th</sup> with the Parkinson's Foundation and the Indiana Center for Excellence, a Women & PD Conference, Fall Parkinson's Symposium, Caregiver Conference and hopefully a couple fundraising events. If you would be interested in helping with any of the upcoming events or would like to plan a fundraiser please contact Sheri at [sheripaaci@yahoo.com](mailto:sheripaaci@yahoo.com) or 317-255-1993. Last year we had a couple of Tea's at Serenity in Zionsville, The food was great, the service was wonderful and all in attendance had a really nice time. Maybe this year you could attend one of the Tea's or have a fundraiser of your own and donate the money to PAACI. We are grateful for your time and donations anyway you choose to share them.

We are also in the process of trying to add a few board members, so if you would be interested in supporting PAACI with your time and efforts please reach out to Sheri at [sheripaaci@yahoo.com](mailto:sheripaaci@yahoo.com) or John at [jdk0304@comcast.net](mailto:jdk0304@comcast.net). Please let us know what kind of volunteering you would be comfortable doing and we'll see where you would fit best.

And thank you to all of you! You are the best part of PAACI and we're grateful for your time, efforts and funds that support our mission. We hope to see you again this year.

Sincerely,

John Deck, Sheri Kauffman & the PAACI Board

# Cognitive Challenges and What to Do About Them

Roseanne Dobkin, Ph. D., Rutgers University Behavioral Health Care, Picataway, New Jersey

About 30% of people with Parkinson's Disease have noticed cognitive changes at the time of their diagnosis. Changes may occur with memory, executive functions, visuospatial abilities, and attention, language, and processing speech.

Difficulties associated with cognitive challenges include decreased independence, medication adherence, diminished quality of life, poorer treatment outcomes, depression, anxiety, care partner burden and safety issues. Contributing factors to this situation are age, disease duration, baseline cognitive impairment, other medical issues, postural instability/gait disorder, REM sleep behavior disorders, motor severity, neuropsychiatric issues, daytime sleepiness, social isolation, depression, limited exercise, diet, and self-care issues.

## Non-Pharmacological Intervention for Cognitive Health

1. Exercise may enhance cognition through neurology and physiology. Studies have shown that with exercise there can be improvement in attention, processing speed, executive function, memory, and spatial cognition. Studies have shown significant improvement in cognition with at least 150 minutes of moderate intensity physical activity per week.
  - a. Aerobic exercise enhances executive function. They recommend 45 minutes of walking 3 times per week.
  - b. Strengthening helps working memory, executive function and attention. Progressive resistance exercise is recommended 2 times per week. Exercise in the form of dance therapy has been shown to help spatial cognition. They recommend dance group of 90-minute duration, two times per week.

Nutrition can modify risk factors. There is a growing interest in nutrition and its relationship to cognition. Nutrition may diminish inflammation and neurodegeneration. Nutrients may have a relationship to increased/decreased risk of PD. The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet lists 10 brain healthy food group which are: green leafy vegetables, other vegetables, nuts, berries, beans, whole grain, seafood, poultry, olive oil, and wine. It lists 5 brain unhealthy food groups: butter and stick margarine, red meat, cheese, pastries and sweets, and fried fast foods. In one study the MIND diet was associated with a 54% reduction risk for Alzheimer's disease, and statistically significant for cognitive function for episodic memory, semantic memory, and perceptual speed.

Cognitive Training: Improvement in executive function may occur with training in serial tasks, matrices, puzzles, speech production, picture completion, storytelling, and sudoku.

Mood Enhancement: Anxiety, depression, sleep disorders, and fatigue may affect mood. Interventions to improve mood may include increasing meaningful and social activity, problem solving for physical limitation, anxiety management, sleep hygiene, and through monitoring and restructuring.

Work with your doctor to be sure your medications are optimal. Exercise and consider a tailored exercise plan. Eat a healthy diet. Consider cognitive training/activities, and above all focus on what you can do.

## Special Thanks....

PAACI would like to offer a special thank to Dr. Deborah Zygmunt. Dr. Zygmunt, who has graciously donated for many years to silent auctions that board member Joann Whorwell organizes, and who this year was photographer at our Holiday Party. We appreciate Dr. Zygmunt, Joanne Whorwell and the many individuals and businesses who support our events.



Dr. Deborah Zygmunt

# Triumph Over Exercise: Maximize your Mobility

Travis Gawler, PT, DDT, Palmetto Health Physical and Specialty Therapy, Columbia, South Carolina

Exercise enhances quality of life, increases insulin sensitivity and reduces anxiety, blood pressure, risk of injury from falls, arthritis pain, dementia, risk of diabetes and hypertension while improving cognition.

## What Type of Exercise? If you choose:

**Aerobic Exercise:** target 150 to 300 minutes per week of moderate intensity or 75 to 150 minutes a week of vigorous exercise. Try to spread the exercise throughout the week.

**Resistance Exercise:** exercise with moderate intensity involving all major muscle groups, 2 or more days per week.

**Flexibility:** Exercise 2 to 3 days per week, with each exercise for about 30 seconds, with 2-4 repetitions. Flexibility exercises help with stooped posture.

**Functional Exercise for balance:** For agility and multitasking exercise 30 minutes, 2 to 3 days per week. Good agility exercise can include yoga, Tai Chi, boxing and dance.

## Preventing Falls

Use support by grabbing counters and doorways and using assistive devices. Exercise with a partner. Prevent fatigue and overuse of injuries. Rest as needed. Consider interval training.

## Attend group exercise classes

## Barriers to considering exercise may include:

- ◆ Low expectations of outcomes
- ◆ Fear of falling
- ◆ Lack of time
- ◆ Other health problems
- ◆ Negative environmental issues
- ◆ Cost

## Positive Strategies:

- ◆ Get educated
- ◆ Set goals
- ◆ Get a fall-risk assessment
- ◆ Try some physical therapy
- ◆ Modify your environment
- ◆ Prioritize your activities
- ◆ Have an exercise buddy
- ◆ Seek free exercise resources

## Strategies for care partners:

- ◆ Involve motivations and education of the benefits of being physical activity.
- ◆ Remind yourself that “Exercise is Medicine.”
- ◆ Start today and never stop.
- ◆ Find exercise you enjoy.
- ◆ Set goals, track progress, and celebrate victories.
- ◆ Develop support for exercise success and adherence.
- ◆ Regularly reassess your routine.

*Thank you! Thank you!  
Thank you!*



*Big Thanks to **Lisa Colleen** who has donated her time and talents while presenting at several PAACI events. She does and did an amazing job of leading the audience in a drum circle.*

*It's good therapy and everyone has such a wonderful time!*

## Caregiving Tips for Caregivers of Parkinson's

If you take care of a loved one with Parkinson's, what does a typical day look like for you? That question may be hard to answer, as any given day likely changes along with your loved one's unpredictable symptoms and a rotating schedule of doctor's appointments, exercise classes and more.

We've compiled a list of practical tips for caregivers of patients with Parkinson's disease to hopefully make their lives easier and to help ease the stress. We've based our advice on information from the Michael J. Fox Foundation and Partners in Parkinson's.

### **Be organized:**

Keep all of your loved one's medical notes, insurance, records, appointments, telephone numbers of clinics and doctors, and medication details in a folder that can be easily accessed at any time. Take this folder with you to all appointments so you always have everything on hand.

### **Look after yourself:**

In order to be able to look after your loved one, you need to be physically and emotionally well. Take time off—it's important to unwind and de-stress. Ask other family members and friends to help out or look into hiring professional care. Spend some time doing something you enjoy and take your mind off things for a few hours.

### **Understand the medical insurance:**

Make sure you fully understand your loved one's medical insurance policy — what it does and doesn't cover and how to apply for reimbursements of medical costs.

### **Join a support group:**

Find out if there are any active support groups in your local area. If not, then look online for a support group for caregivers of Parkinson's disease patients. This will give you both practical and emotional support, and you will be able to ask advice and share your experience with others who are going through the same thing.

### **Educate yourself about Parkinson's disease:**

Keep up to date with all the latest news about the condition, read up about symptoms and talk to your loved one's doctor about what to expect with the progression of the disease.

### **Expect changes in the relationship:**

Mood swings and depression are common in Parkinson's disease and your loved one may even become resentful. It's difficult to deal with these changes in the relationship, so open and honest communication is critical. You will both need time to adjust to your new roles in the relationship.

### **Observe symptoms and report any changes:**

As your loved one's carer, you will probably be the first person to notice any changes in behavior or worsening of symptoms. Report these to your loved one's doctors as they occur so they can be addressed as soon as possible.

### **Encourage independence:**

Try not to do too much for your loved one, they will want to hold onto their independence for as long as possible. Ask if they need help and respect their answer.

### **Know your rights:**

Familiarize yourself with both caregivers' rights and disability rights. Find out if you are entitled to any disability or carer's benefits.

### **Talk about the future:**

Although this is a difficult topic to broach, it's important that you understand what your loved one wants further down the line. You need to discuss wills, treatment options and end-of-life decisions.

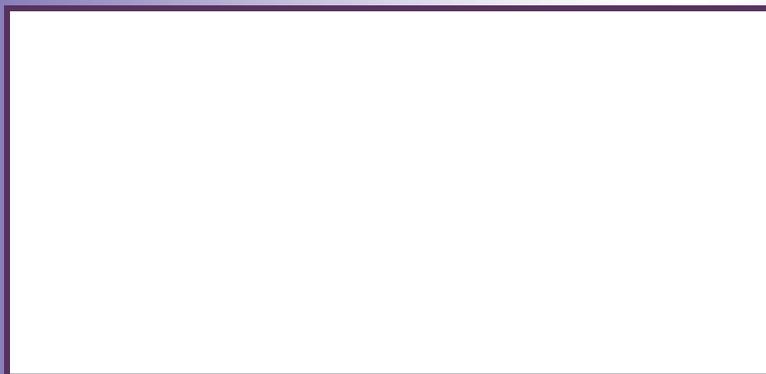
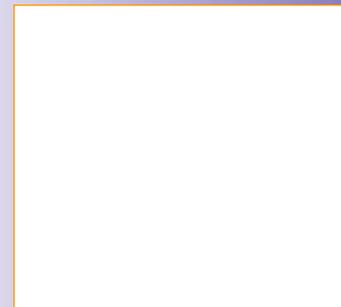
Source: Michael J Fox website, and Partners in Parkinson and caregiver's alliance.



# 2019 PAACI Holiday Party



**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, 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](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: \_\_\_\_\_