Jan-March 2016

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

Indy PD Update

Parkinson's Awareness Month Mini-symposium

Presented by:
The Parkinson's Awareness Association of Central Indiana, Inc.

Saturday, April 30, 2016 (12-4 pm)

Topics include:

Kate Kunk from the Central Indiana Council on aging (CICOA) and what it has to offer including a resource center, caregiver support, transportation, meal assistance and home modifications

Courtney Johnson, PhD, HSPP
Assistant Professor of Clinical Psychology in Clinical Psychiatry, IU School of Medicine
Topic: Practical Stress Management Techniques to Promote Health

Pre-registration requested. Please contact Sheri at 317-255-1993 or skauffman@paaci.org.

$10 Per Person
Includes light lunch

12p-1pm
Martha Klemm, Harpist

1-2pm
Kate Kunk from CICOA

2-3pm
Courtney Johnson, Ph.D. from IU

3-4pm
PD Jeopardy

We will also have:
a silent auction, fresh tulips and Parkinson's information

At the PAACI Office located at
6847 Hillsdale Ct., Indpls, IN 46250
Inside Rock Steady Boxing

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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

PAACI Board Members

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Jeff Brodzeller –**Treasurer**
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Newsletter

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

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Arranged & Edited by Sheri Kauffman

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.

Upcoming Events:

Mark your calendars and save the date!

PAACI Mini-Symposium—
Saturday, April 30, 2016
See cover for details or call Sheri at 317-255-1993.

Calling All Support Groups…

Did you know that the PAACI Office has an abundance of information that you can pick through and take to share with your support group members? If you or someone from your support group would be interested in coming to pick up information please call Sheri at 317-255-1993.

PAACI Office—317-255-1993

Helpful Phone Numbers

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

Dr. Ruth Ann Baird—317-217-3000

Dr. Joanne Wojcieszek & Dr. Liz Zauber—317-944-4000

Chair exercise classes—317-872-4567

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

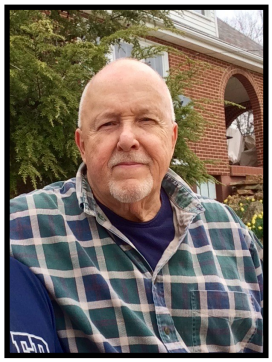
Shelby Cty PD Exercise & Support—317-398-7614
(Currently limited to Shelby County residents and Major Health Partners patients)

Westside Support Group—317-244-4463

Young Parkinsons of Indiana—317-203-3049

Parkinson's Action Network (PAN)

Presented at the Sunday Education Meeting in November 2015
By: David Armstrong, Indiana Assistant State Director



PAN is a nonprofit national, grassroots, advocacy voice on public policy issues, unified behind the ultimate goal of finding a cure for Parkinson's disease. PAN was founded in 1991, by Joan Samuelson, a person with Parkinson's disease, and it costs about 1.6 million dollars annually to run. The organization has been an advocate and over the years has helped find research funds. For the FY2016 budget they are supporting a request from the National Institute of Health (NIH) for 32.4 billion dollars. In FY 2014, NIH funded 139 million dollars for Parkinson's disease research. PAN also supports funding for PD research done by the Food and Drug Administration (FDA) and the Department of Defense (DOD). PAN advocates on behalf of the entire Parkinson's community.

PAN has three programs:

Public Education: This includes web casts, video websites, as well as printed materials.
Government Policy: This includes research for treatment and a cure along with current care.
Grassroots Outreach: The building of a base of e-advocates.

Grassroots programs may involve various levels designed to fit your skills and time availability. Anyone can be an advocate. There is no prior experience or training needed. You work within your abilities and connections with your local members of Congress.

How can you help?

Sign up for action alerts. You will need to provide an e-mail address and your zip code.
Take action: it will take less than 5 minutes for you to contact your congressional representative.
Tell family and friends.

The PAN Forum

A meeting is held every other year in Washington, D.C.. Advocacy training is provided, news on the latest research and public policy issues are communicated, and you get a day of advocacy in the nation's capital.

-There are 500,000 to 1.5 million Americans with PD, including 80,000 veterans.
-The Department of Defense has spent 340 million dollars on research for PD since 1997.
-PD costs our country about 14.4 billion dollars a year.
-It is anticipated the prevalence of PD will more than double by the year 2040.
-PAN has supported the National Institute of Neurological Disease and Stroke (NINDS) and the Morris K. Udall Centers for Excellence for Parkinson's Research.
-PAN helps deter closures of centers that treat PD.
-PAN is the leading advocacy voice for PD issues and Medicare, and works with the FDA revitalizing the patient engagement campaign.

To sign up to be a PAN advocate contact the PAN Office at 800-850-4726 or info@parkinsonaction.org or for more information visit www.parkinsonsaction.org or contact David Armstrong at 812-926-3679 or at darmstro43@embarqmailorg.

This Newsletter partially funded by the Dee Garrett Grant Fund.

The President's Corner...with John Deck

- In celebration of Parkinson's Awareness Month we are pleased to offer our April 30, 2016 Mini-symposium. April is also PAACI's 35th Anniversary and we hope you will join us. Information about the seminar is featured in this Newsletter.
- Memorial Day's coming along with the 100th running of the Indianapolis 500, which is a big thing in Indiana, also known as the "greatest spectacle in racing." PAACI would like to wish a special welcome to our Al Malaikah- Murat Shrine friends who have recognized and help support PAACI during their annual visits over the years, and who will also be celebrating their 35th year of attending the race week events.
- And last, but not least, in the true spirit of Memorial Day it is a special time to honor the veterans who have served and to remember the more than eighty thousand living American veterans who have been diagnosed with Parkinson's disease as a result of exposure to Agent Orange and other herbicides during their military service. We salute you!

Please check our web page (paaci.org) and our Facebook page (Indianapolis Parkinsons) for the topics of our upcoming monthly educational meetings.

Michael J. Fox Foundation for Parkinson's Research

Presented at the Sunday Education Meeting in January, 2015
By Kristen Milliron

Kristin has been with the organization for 3 years. The goal of the foundation is to promote research to find a cure for Parkinson's disease and to go out of business. The organization has 11 ambassadors, and Kristine is an advancement officer. The foundation was launched in the year 2000. It is the world's largest not for profit funder of Parkinson's disease research.

It takes 15 to 30 years to bring a new drug to market, and often well over a billion dollars

There are different areas of research:

Basic research that looks at some molecular process, and why is it important. At this level taxpayers spend more than 30 billion dollars on research through the National Institutes of Health.

Transitional Research looks at the discoveries often with the molecular process in relationship to diseases. Many research ideas do not advance beyond this phase.

Clinical research is where a potential new drug enters the human testing process. This is a lengthy, multi-phased process. Each of the three phases of clinical trials take larger numbers of subjects. Trials have to be designed, volunteers for tests recruited, data collected, findings analyzed, and preparations made for FDA approval. Each of these phases takes money, and about $70 billion a year is spent on this phase of clinical research. Most of this money is from private investment and drug companies. Eighty -five percent of clinical trials face delays. Only one in 12 clinical research projects are approved safe and beneficial.

Collectively about $100 billion is spent a year by the NIH and private investment on drug research.

The Michael J. Fox Foundation has promoted research development with hundreds of millions of dollars. 90% of their funding goes to promoting transitional research which is investing in identifying and encouraging the development of ideas for research that are most likely to have the impact on human health. They will fund the scientist and the lab, helping to take a study through the early stage and help it get funding. They promote research that moves us closer to new therapies. They search for biomarkers: that one test to conclusively diagnosis the disease. They promote the study of genetic mutations, and alpha-synuclein. They are investing in research of disease modifying strategies to slow down or stop the progression of the disease, as well as asymptomatic therapies that will produce benefits relieving symptoms.

On the Michael J. Fox Foundation web page is the Fox Trial Finder that will match you up with clinical trials. You are encouraged to register, complete your first virtual visit, come back every 90 days, use your helpful tools, and impact PD research. You can also go to Fox.insight.org which presents a record of tracking your symptoms between doctor's visits. The Fox Foundation also has Webinar: a webcast the 3rd Thursday monthly.

Symposium Questions and Answers

Do European researchers collaborate with US researchers? Why does US research take longer?

Dr. James: Europe may be a little less cautious about new research. The FDA is very particular and a little stubborn, and we are very thankful they are protective of the citizens served. There are differences in requirements for research between countries. The FDA does its due diligence.

Dr. Daly: More trials are done overseas probably due to differences in laws and patient protection.

Before getting a license to practice Neurology, is there any requirement for the doctor to spend 24 hours a day to provide care for brain damaged patients including Parkinsonians?

Dr. Daly: There is no license to practice neurology. There is a license to practice medicine. If you complete one year of internship in neurology, you can practice neurology. If you go on and complete a 3 year residency in neurology, only then can you become a board certified neurologist. You should only go to a board certified neurologist.

Is there a public access site describing care providers, and how they are receptive to patient's needs...like Angie's list?

Jane Malkoff: There is no neutral list. You have to pay a fee to be on Angie's list. The state of Indiana has a running list of providers who have complaints. There is no way you would know if the complaint about the doctor is warranted. The best way to find the best provider is by "word of mouth," and meeting with them.

I am 61, still working full time. Next year I turn 62 and at 63 I have to stop working. Can I draw normal social security and still file for disability?

Leo Rafail: This is an individual situation. The process of applying for disability involves working with a good physician to document your history. It should not be difficult. Do things methodically and complete the application. You should contact the social security office and have them do a comparison of retirement dates and benefits to determine when it will financially make sense. You should include the issue of insurance and Medicare, not just for yourself, as it may also affect insurance for your family.

Regarding Lewey bodies. We all have them in the gut. Has it been determined why we do not all have PD? Are there more Lewey bodies in some people than others?

Dr. James: You can have Lewey bodies in your gut and not get PD. We do not know yet the direct correlation with the amount of Lewey bodies in the gut. But we do know there is a connection.

Are there quinine drugs for PD?

Dr. Daly: Doctors are forbidden to prescribe quinine for anything except malaria. The reason they took quinine off the market was because it may induce cardiac arrhythmia.

Of all care providers here today, who solicits or is receptive to patient research?

Dr. James: There are early phase drug trials ongoing.

Leo Rafail: Dr. Miller is comparing different types of therapies to Rock Steady Boxing exercise. Dr. Barbara Haberman does survey studies that look into other types of therapies Parkinson's patients are doing.

My mother has PD. She has begun going through things and saying they are not hers, but belong to her husband's girlfriend. How do I handle this?

Dr. James: Cognitive changes can be associated with PD. There can be a dementia type illness or a reaction to medications. It can be related to hallucinations. More often than not it is part of the disease itself.

Jane Malkoff: It doesn't pay to try to reason with those who cannot reason. Just help them the best you can. Be empathetic, supportive, and try to redirect the topic, or distract them to a different activity.

Does PD cause weight loss? No matter what we do to prevent weight loss, it doesn't work.
Dr. James: Weight loss is **NOT** usual unless the person with Parkinson's has a swallowing problem. Also, people with late stage PD may have a reduced appetite. Weight loss often happens later in the disease particularly if the person has dyskinesia.

What do you know about amino acid treatment?
Dr. Daly: Amino acids are building blocks. In PD, the cells are dead and are not there to take the amino acid where it needs to go.

What is the cost of Rock Steady Boxing Classes?
Leo Rafail: Contact your local Rock Steady Boxing affiliate program. There are some subsidies at some programs. At the Indianapolis headquarters costs $60 a month.

Can you speak to PD with early onset dementia and late onset dementia?
Dr. James: Dementia can happen. We like to see it much later. If it is early they investigate to see if it is Lewey body dementia. You are better off getting late onset dementia.

Does medical marijuana help PD?
Dr. James: There have been some small studies done, but it's hard to study something illegal. There have been some small neurological studies on the use of cannabinoids with epilepsy. The verdict is still out, but it is unlikely it will be beneficial for PD.

Have You Heard Of Parky The Raccoon?

Information courtesy of the worldpdcoalition.org

Where did Parky come from?
In the summer of 2012, Bob Kuhn who was a WPC 2013 Ambassador took a 70-day trip around the world to meet other people with Parkinson's and the organizations that support them. Parky, or at least a cardboard cut out of Parky, traveled with him. He helped Bob relay his travels to his then 3 1/2-year-old grandson and Parky was often the bridge between Bob and people with Parkinson's who could not speak English. Everyone was curious about this strange animal, which is indigenous to North America and virtually unknown in the global South. It was a way to promote the World Parkinson Congress 2013, but in the end, this was how Parky became the WPC mascot.

Why Adopting A Raccoon Made Sense For People With Parkinson's?
1. The distinctive mask, which represented the "Parkinson's mask".
2. Raccoons are inventive when faced with challenges. Excellent problem solvers, with a high level of curiosity and the ability to survive in highly diverse environments, raccoons are considered to be one of the most intelligent mammals.
3. Raccoons are often nocturnal, but not exclusively so. Parkinson's affects sleep.
4. They can be mischievous. After all, Parkinson's disease is serious enough in itself. It's good to have a little fun.

ICAN (Indiana Canine Assistant Network)

Presented at the Sunday Educational Meeting on February 21, 2016
By: Sally Irvin, Ph. D., Founder and Jillian M. Miller, Executive Director

The Indiana Canine Assistant Program (ICAN) was founded in 2001 by Dr. Irvin based on her belief that service dogs can be catalysts for positive change in peoples' lives. ICAN is based in Indianapolis but serves a 250 mile radius of Indianapolis. They are the only accredited canine service program in the state, with certification from Assistance Dogs International. ICAN began at the Pendleton Juvenile Correctional Facility, where incarcerated adolescents interacted with the dogs-in-training. The program has evolved to
engage the abilities of adults incarcerated in Indiana correctional facilities to conduct intensive training to prepare the dogs for service work.

Dogs for this program are purposefully bred. The mother is a Golden Retriever, and the father is a Labrador Retriever. These breeds are chosen because of their temperament and health. The puppies begin training at 3 weeks of age, and are weaned at about 8 weeks of age. They start training at the men's prison and at 18 months of age they are sent to the women's prison. There is a contingency of many volunteers (more than a hundred) who work with this program outside the prison environment for the canine to have experiences in a more natural work environment like shopping and navigating public places. More than 120 dogs have been trained in the past 13 years, and currently there are 50 dogs in training. The training is a remarkable partnership.

On the national level, the success rate for a dog entering and completing training is 50%, and ICAN is proud of its success rate of 60%. There is approximately a 2 year waiting list from the time of requesting a assistant dog, until one can be trained. The cost is a $1600 fee for the dog. It actually costs $26,000 to train the dog. Owners sign an agreement that they will be responsible owners and follow the rules. There is a two week training program initially. It is important that the canine will remain healthy, and there are follow-up visits, a minimum of twice a year, to check on the animal and owner. If for some reason the owner cannot continue benefiting from the dog they have a program for what they call a “career change dog facility.” However, if a family has become attached to the dog, they are allowed to keep it.

They brought a 19 month old trained dog (Senator) and a 9 week old puppy (Winky) in training with them and demonstrated there abilities to assist with helping to remove gloves, and picking up items requested or dropped.

How can an assistant dog help you?

An assistant dog can help with:

Mobility assistance: This may include helping the person keep a steadier gait, and some balance issues, and helping them more safely stand up or sit down, as well as some assistance if “freezing” occurs. Dr. Irvin noted that balance assistance is one of the hardest things to address but with special training of the canine there have been benefits.

Diabetic alert

Facilitation of therapy: helping them do therapy activities such as playing catch and retrieving what is thrown, pulling exercises, stretching, and of course walking and keeping up endurance.

Veteran's with post traumatic stress disorder (PTSD) and physical limitations have been benefited. Some small recent studies have noted that stroking the pet dog elicits a release of a number of good hormones such as serotonin, prolactin, and oxytocin, It may also decrease levels of the stress hormone cortisol, the chemical that regulates our appetite and desire for carbohydrates.

Autism patients are often more focused when they have the assistance dog.

Dr. Irvin commented that individuals who may benefit from an assistant dog often wait longer than they should to request one, and should consider making application to get an assistant canine sooner.

ICAN (Indiana Canine Assistant Network) may be contacted at 5610 Crawfordsville Rd, Suite 2101, Indianapolis, IN 46224. Phone 317-672-3661 or e-mail: jillian@icandog.org should you have any questions.

Parkinson's Awareness Association of Central Indiana, Inc. (PAACI)
6847 Hillsdale Ct., Indpls., IN 46250
317-255-1993 www.paaci.org
Facebook: Indianapolis Parkinsons
Email: skauffman@paaci.org

PAACI Office Hours:
Monday-Thursday
9am-3:00pm
Phone hours:
Monday –Friday
9am-5pm

Home Instead SENIOR CARE®
(317) 252-4472

PAACI Announces The Tulip Society

We are launching the PAACI Tulip Society as our way of recognizing and honoring those who wish to ensure our mission is continued. The PAACI mission is for us to be a major source of information and education about Parkinson's disease and a strong advocate for improvement of services, quality of care and research support for people with Parkinson's disease in Indiana. We have chosen to call this initiative "The Tulip Society." The tulip became the recognized symbol for Parkinson's in 1980 when a Dutch horticulturalist J. W. S.Van der Wereld honored Dr. James Parkinson, author of the first published work to describe Parkinson's (1817), by naming a new tulip he developed after him. The Parkinson's disease Foundation was first to use the three petal tulip as it's symbol of "hope through research, education, and advocacy." Annual donations in the amount of $100-249 will be symbolized by the pink tulip which represents friendship and caring. The members of the Pink level would receive a 20% discount on event tickets and their donation would include their annual dues.

Annual donations of $250-$499 will be symbolized by the orange tulip meaning warmth, happiness and enthusiasm. Orange level donors will receive a 50% discount on all event tickets and would include their annual dues.

And donations of $500 or more will be symbolized by the purple tulip which denotes generosity and devotion. Purple level donors will be acknowledged at each event (unless requested otherwise), receive a Purple Society Tulip pin, receive free admission to all PAACI events and includes PAACI annual dues. Every level of the Tulip Society will be recognized in each of our Newsletters for the year that they are a member of the society. We hope you will honor us by making a timely donation to help us sustain our mission and become a member of our inaugural Tulip Society campaign.

PRODUCED AND DISTRIBUTED BY: PAACI

It's Time to PAACI UP!

Hi Friends -

We are approaching April, which is Parkinson's Awareness Month and the 35th anniversary of PAACI's inaugural meeting. So, I want to introduce a campaign for those who participate in the services and benefits of PAACI and it's Newsletter (this Newsletter) and to remind them of the importance of being a dues paying member. The dues help assure that we can continue to support our core values of Awareness, Resources, Education and Support. This membership dues campaign we are calling "PAACI **UP**". As a PAACI board member I was asked to step **up** to this task. I called **up** Nancy and Sheri. They said "What's **up**?". I told them my plan and they decided to back me **up**. I stayed **up** all night and thought about it. I brought it **up** with friends. They are backing me **up** too! I wanted to own **up** that I was **up** to something: continuing our mission I think is important to you. I'll own **up** to this. Yes, I am building you **up**. We want to gang **up** on living fuller lives with Parkinson's, and finding a cure. I hope you get worked **up** about this. We don't want to leave it **up** to chance. I won't give **up**, so help us pick **up** the tab by paying your dues. I had better wrap this **up** and clam **up**. I'll leave it **up** to you. Thanks to all of you who are dues paying members to PAACI, and I encourage all of the rest of you to stand **up** or step **up** and join. It will cheer you **up**! Thanks for letting me talk you **up**. I hope you join me now and **PAACI UP**.

Sincerely -John Deck

Yes, It's Time For Me To PAACI UP!

My Name is:_____

My Address is:_____

My Phone # is:_____

Method of Payment: Check_____ Cash_____

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

Credit Card Number:_____CVV Code:_____

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

Signature:_____

Please mail to PAACI at 6847 Hillsdale Ct., Indpls., IN 46250

Memorials, Dues & Special Donations

In Memory Of:

David L. Brown - Kenneth Barkdull

Patricia J. Buchanan - Raccoon Village Association

Larry Chamberlain—Jennifer & Nathan Storey

Floyd Chandler—Mary Skinner

Helen Hodges Spradling -Patty Brotherson, Lisa & Thomas Deinlein, Kathlenn Gill, Alisa Hendrix, Nancy Nelson, Ann Whitlatch

Norman Knoy—Ruth Johnson

Midge Lackey—Bill Froelich & the Al Malaikah-Murat Shrine

David Ockerman– Stefan & Sharon Bathory, Annette Millikan, Carol & Martin Zagarinsky

Mary J. Potter—Patricia Colvin, Margaret & William Maynard

Edwin & Marjorie Schulz—Mary & Paul Fleener

James N. Skinner—Mary Skinner

Helen Spradling—Lisa Eshelman, Kristie Utter & family

David Stettler—Larry Puls

Howard Storms—Robert Hobbs

Nora Utken— M. Patricia DeVito, Judyth Lessee

Alan Howard Voorhis—Jeffrey Arbogast, Byron & Jean Ann Voorhis, Ron, Barb, Connie & Jim Wright Family

Donald Wilson—Patsy Wilson

Doug Wilson—The Holstine Family

Franklin Nash Wininger—Steve & Jane Dalzell, Washington Church of Christ, Twentieth Century Chevy

Honorarium:

A special donation was made to PAACI by Denise Dickson in honor of ***Mike McConnell*** whose living his life beautifully with PD.

Thank you so much to all our dues paying members. Every donation makes a difference!

2016 Dues Paying Members

John Deck, Gregg & Ann Grosh, John & Martha Ladd, Barbara Roy and Charles Waldo.

2015 Dues Paying Members

John & Mary Lou Adams, Dave & Connie Beery, Lanie Bertram, Glen & Jeanne Bohannon, Kimberly Bowden, Beulah Bozenski, Jeffrey Brodzeller, Jerry & Phyllis Brown, Joe Carney, Kathy Chudyk, Stephanie Combs-Miller, John Deck, Larry & Cheryl Dilk, Richard Doran, Ahmed ElAntably, Marilyn Fini, Joan Dearmin Finney, June & Susan Fisher, Robert/Stuart Fort, David Garrett, Charlene & Leonard Gringlas, Gregg & Ann Grosh, John Gross & Rosemary Vania, Grand Travers Area Parkinson's Support Groups, Linda Hinkle, Chuck Holdeman, Kay Johns & Caroline McNelley, Martha Klemm, John & Martha Ladd, Lucinda Laughlin, Carl Lutz, Barb Mathauer, Mary & Charles Matsumoto, Linda McGinnity, Lettice Otero, Robert & Deborah Pardue, Rebecca Parks, Christine Pierle, Gregory & Julie Powers, Nancy Pressner, Randy & Jayne Rains, Tom & Marilyn Ransom, Barbara Roy, Ellen Schemmel, Betty Shewman, Donald Shuhldreher, Michael & Paula Slinger, Richard & Susan Szep, Brenda & Charles Tarzian, Rick & Carol Thorne, Tom Timberlake, Paula Tomlin, Stephen & Laura Vollmer, Charles Waldo, Terri Weymouth, Joann Whorwell, Clara Wyrick and Carol & Martin Zagarinsky.

Funny Corner: The second mouse gets the cheese.

Courtesy of Parkinsonian People

Special Donations from:

Connie Beery, Causecast Foundation, Robert & Deborah Pardue, TheSchrader Community Fund, Thomas & Barbara Stayton Fund, Jeff Stinson, Rick & Carol Thorne