

IN THIS ISSUE

In Loving Memory of Morvarid Karimi, M.D.	1-2
Exercise Space Opens!	2
When Are You Disabled by Parkinson's?	3
Productive Work and Parkinson Disease: Questions, Answers and Resources	4-5
A New Treatment for Psychosis in Parkinson Disease	5
Putting for Success – Another Perfect Round!	6-7
Parkinson Plus Syndromes- MSA, PSP, CBS, Vascular Parkinsonism	8-9
Cocktails & Conversation	9
Tributes and Donations	10-11
Optimism Events	12
Support Group Calendars	13-14
Exercise Class Calendar	15
Save the Dates 2016	16



American Parkinson Disease Association

APDA Greater St. Louis Chapter

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In Loving Memory of Morvarid Karimi, M.D.

1971 - 2016

As many of you know, the world and our Parkinson community lost a wonderful person when Dr. Morvarid Karimi passed away so unexpectedly in May, following hospitalization with a ruptured aneurysm. She had been gradually improving during her three week hospitalization but could not survive a second major brain hemorrhage which took her life on May 21, 2016. Johanna Hartlein, nurse practitioner, wrote in her Facebook tribute to Morvarid, "I lost a part of my heart. I lost a literal genius colleague, a treasured mentor and an irreplaceable friend. She never treated our patients as a diagnosis but instead saw every patient as an individual and treated each person differently depending on that person's needs. She mentored me not just

at work but in life, showing me the rewards of living a life of service and teaching me to do so quietly because the world may never know our acts of kindness but we ourselves will know. She taught me to be a good person especially when no one was watching, because goodness is not about recognition but about respect for others.

"Morvarid was a real force in our group. She was always tenacious and committed."

She was honest to a fault, never one to sugar coat or to beat around the bush...completely forthcoming but always with a gentle hug and word of encouragement. She taught me to advocate for our patients, to never be above the necessity to spoon feed a person, to wipe their noses, to hold their hands. She taught me that it is not at all unprofessional to hug or cry with someone because it is our humanity that makes us real and our

continued on page 2

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OUR MISSION

Our mission is to enhance the quality of life for people with Parkinson disease, their families, and caregivers in our communities throughout Missouri and Southern Illinois, and to provide funding for ongoing Parkinson research.

Disclaimer: The information and reference material contained herein concerning research being done in the field of Parkinson disease and answers to readers' questions are solely for the information of the reader. It should not be used for treatment purposes, rather for discussion with the patient's own physician.

IN LOVING MEMORY OF MORVARID KARIMI, M.D. *continued from page 1*

humanity that makes our patients love and respect us most.”

Dr. Joel Perlmutter, Head of the Movement Disorders Section and Medical Director of the Greater St. Louis APDA, shared the following message with the staff after Dr. Karimi passed that Saturday afternoon in May, surrounded by her husband, two children and other family members and colleagues.

He wrote, “Morvarid was a real force in our group. She was always tenacious and committed. She was incredibly protective and good with her patients – as many of us know having covered for her these last few weeks. She would go the extra 10 miles to make sure that she did everything possible to help them.

“She was also incredibly bright and hardworking. She approached research with the same spirit that she approached patient care – with meticulous attention to detail. I always knew that any work that she was ready to publish was checked, checked again and rechecked. She was not blinded by her own or my bias for the ‘right answer’ – rather, she wanted the correct answer.

“She also continued to fight for the rights of women in our society, especially in the workplace. She had a strong sense of fairness and wanted everyone to be treated

appropriately and equally. As we know well, she never shied away from making that clear. She was a real champion of women’s rights.

“Most importantly, Morvarid loved her family. She loved her two children, Kyan and Suri, and her husband. She talked about their accomplishments and their challenges. She made sure that the kids would have as much opportunity to learn as possible. Clearly her two children have their mother’s intellect and force of character.”

Dr. Perlmutter shared that Dr. Karimi had made clear her wishes to donate her organs for transplantation – still demonstrating her concern for other people’s welfare. In fact, it was reported that by the Monday following her passing, there were several survivors who now carry a piece of Morvarid with them. We can only hope that her influence will guide their lives in similar ways.

As Johanna said, “Morvarid had so much yet still to offer to the world, so many lessons to teach, so much research still to conduct, so many hugs still to bestow, so much love still to give.” May her memory be for a blessing, and may we always keep fighting the good fight in Dr. Karimi’s honor. May this be so! ■

“She had a strong sense of fairness and wanted everyone to be treated appropriately and equally.”



EXERCISE SPACE OPENS!

We are happy to announce that the lease has been signed and the suite next door to our Center in Chesterfield, Suite 163, has

undergone remodeling to accommodate our exercise programs. By the time you are reading this newsletter, we will be featuring some new exercise classes in addition to the three levels of Tai Chi and meditation with Craig Miller and Monday afternoon chair-side and circuit training exercise classes with Tricia Creel. In addition, conversations and discussions are taking place to add Yoga, Tango, and Delay the Disease classes.

Contact the Center at 636.778.3377 to learn how you can participate in these exciting new classes or to become a benefactor of this wonderful new space.

When Are You Disabled by Parkinson's?

Paul Short, PhD, Neuropsychologist, The Parkinson's Coach

Parkinson disease (PD) is a physically disabling condition, but when does it become a disability that degrades a person's job performance?

There is no simple answer for this question. PD presents in a variety of ways and each person must respond to both the disease and their own unique employment demands. The only reasonable response is that whether or not the disease is changing or impairing work performance is a product of many variables that must be assessed by each person on an individual basis.

Self-assessment is never an easy task, even under the best of circumstances. It becomes particularly daunting when it involves evaluating how severely PD is affecting not only one's livelihood but also the very career producing it. However, as difficult as a self-evaluation may be, it is far better than letting circumstances move beyond your control and decide for you.

The problem is that too many people with Parkinson's fail to undertake even the most rudimentary assessment of what PD is doing to their job performance. Fear, depression, anger and sometimes a wishful hope that effective treatment will make self-evaluation unnecessary can lead to a decision to kick the can down the road. So can a "tough it out" strategy that simply ignores the reality of the disease by pretending nothing is wrong, work?

I am a strong proponent of men and women who have PD working as long as they are able. I have seen too many clients, confident that their job performance was fine, faced with unexpected termination or long-term disability because they did not understand how PD can impact performance. The devastation of being told to move on because of PD only makes the unfairness of a life-altering illness all the more bitter.

The problem with a progressive disease is that options tend to become fewer and even foreclosed upon over time. Think of the example of investment opportunities for a retirement vehicle like a 401K. An account opened a few years before retirement provides nowhere near the growth potential or financial flexibility that one opened decades earlier

provides. As with retirement planning, the need for a frank disability assessment should begin as early as possible.

So what are some points to consider in a self-assessment?

The first, and most neglected step, is to determine what you actually do on the job. Job titles and generic professional designations (attorney, accountant, etc.) are not sufficient for this task. It is more important to know what activities your company calls on you to do during the course of a day, week, or month. Make a list of these and keep adding to them as new tasks become apparent.

Now, consider each of the job demands you have identified and ask yourself how your PD symptoms might affect it now and in the future. This may be a good time to ask for input from a trusted colleague or family member. For this step, it is important you not allow yourself the luxury of optimism; assume the worst during this mental exercise and the chances are that actual outcomes are, or will be, less severe.

Next, write down a couple of compensatory responses to the real and potential effects of PD for each item on your list. These can form the basis for immediate change or be stored away for action at a later time. They may also form the basis for a request for possible accommodations from your employer when that time comes.

Finally, review your list periodically and revise it as necessary. A good rule of thumb is to look at it immediately after a visit with your neurologist. You might even want to share elements that concern you with your doctor.

Remember that an assessment of this kind can be both painful and proactive. However, it provides maximum flexibility in your fight against Parkinson's disability by keeping you at work for the longest time possible, and, equally important, it allows you to determine when Parkinson's has truly disabled you. ■

For more information on how to perform a job evaluation, see the article [Productive Work and Parkinson Disease](#) appearing on the following pages.



Productive Work and Parkinson Disease: Questions, Answers and Resources

Mary Seaton MHS, OTR/L, Senior Clinical Specialist, The Occupational Performance Center at The Rehabilitation Institute of St. Louis

notice that my symptoms are changing my performance or interactions at work. What should I do? Should I tell my boss about my medical condition? Does the timing matter? What are my rights if I want to protect my job? I want to remain active & productive as long as possible. Should I apply for disability benefits at some point? If so, when?

So you have a job that you love or you need, or both, and you have been diagnosed with Parkinson disease. Maybe you have noted a physical change or symptom, such as pain, fatigue, limited endurance, or decreased movement control which may impact your interactions at work. You worry or wonder if you should tell your employer about your diagnosis now, or if not now, when?

If this or a similar scenario applies to you or to someone you care about, this article is intended to begin the process of education and identification of your rights and resources.

First, you need to decide if the symptoms are affecting your ability to perform your job in any way. It is particularly critical if your performance of the job essential functions is affected.

What are “essential functions”? Essential functions are the core duties of the position—the reason the job exists. Often you will know if your limitations affect a core job duty rather than a peripheral responsibility. If you or your healthcare provider need details to assist in making job adjustments, you may need a written job description to identify essential functions for your position.

If there are changes in your physical or cognitive function that affect the performance of essential functions, have others on the job noticed them? It is possible that your employer or work colleagues may detect a change in your interactions or in the physical skills that affect your performance before you are aware of it. In that case, you may be approached by your employer first, regarding what they may perceive are negative workplace performance behaviors. In general, symptoms that change performance are most effectively addressed proactively or as you notice them.

This brings us to a point of discussing your rights as an employee. Under the Americans with Disabilities Act, you have a disability if you have a physical or mental impairment that significantly limits or restricts a major life activity such as hearing, seeing, speaking, walking, breathing, performing manual tasks, caring for yourself, learning or working.

If this definition fits your situation and you are qualified to do a job, the Americans with Disabilities Act (ADA) protects you from job discrimination based on your disability. If you have a disability, you must also be qualified to perform the essential job functions, with or without reasonable accommodation, in order to be protected from job discrimination by the ADA.

What is “reasonable accommodation”? Reasonable accommodation is an adjustment or change in the employee’s routine, job task or environment that enables a qualified employee with a disability to perform the essential functions of a job. An employee who can’t perform the essential job functions, even with a reasonable accommodation, isn’t considered qualified for the job and isn’t protected from discrimination.

Examples of reasonable accommodation may include:

- Use of equipment, devices or strategies
- Restructured job tasks or positions
- Modified work schedules or timing

The reasonable accommodations must not cause an undue hardship or expense for the employer; thus what is “reasonable” will vary based on the size of the employer.

When the time comes to request reasonable accommodations



that your employer can help you with, you need to identify who/how to initially report to at your place of employment, possibly the human resources representative or your manager. When meeting with your employer, you may not initially choose to tell them the name of your diagnosis but rather that you have been diagnosed with a medical condition that results in specific limitations or limits your ability to perform specific aspects of your job. Ideally you should be prepared to offer or discuss ideas for adjustments that will allow you to perform the essential functions of your job up to the expected standards.

Certainly this is a lot to take in, particularly in the presence of a new and potentially stressful situation for both the employee and the employer. The Washington University Occupational Performance

Center offers services and support provided by specialized occupational therapists. Their assistance can provide employee education, strategies, and advocacy to make informed decisions and actions.

Examples of interventions they can provide include:

- Identifying modifications or accommodations for work, school or volunteer roles.
- Helping clients find ways to manage chronic or progressive conditions and to advocate for themselves in meeting goals and performing meaningful roles.
- Exploring possible options for employees needing a new role.

- Evaluating assistive technology and equipment or computer technology needs.
- Meeting with employers regarding performance expectations and employee advocacy.
- Helping clients transition to disability status or a productive volunteer or retirement role.

If you think that you or someone you care about may benefit from working with the therapists in the Washington University Occupational Performance Center (OPC), talk to your physician about a referral. You or your physician can call the OPC at 314.658.3881 for more information. ■

A New Treatment for Psychosis in Parkinson Disease

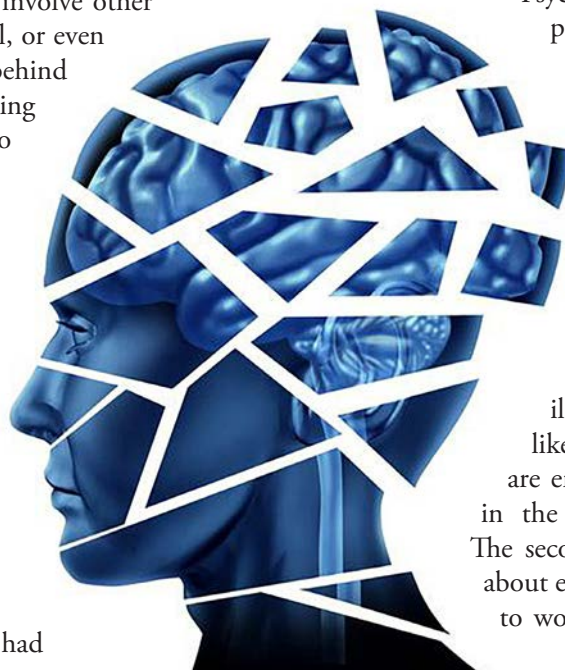
Kevin J. Black, MD, Professor of Psychiatry, of Neurology, of Radiology, and of Neuroscience, Washington University School of Medicine

Early in the course of Parkinson disease (PD), treatment usually goes well. However, after five to ten years, things start to change as treatment requires higher doses of medications and side effects become more problematic. One of the most difficult problems, and one that surprises many patients and families, is the development of psychosis. The word “psychosis” often has very negative connotations to lay people, but in this medical setting, psychosis means hallucinations or delusions.

A hallucination is when one of your senses tells you something is there but it isn't. In PD, the most common hallucinations are seeing things that are not there, like seeing someone else at the dinner table or seeing small animals run across the floor. Hallucinations can involve other senses as well: hearing, touch, taste, smell, or even that creepy feeling that someone is right behind you. A delusion is a firm belief in something that is not true despite clear evidence to the contrary. Sometimes delusions seem to arise to explain hallucinations (*e.g.*, you hallucinate a person in the house, so you tell your spouse that people are breaking into your house to steal the china). Other delusions can involve themes of persecution, jealousy, or theft. Hallucinations are more common in PD than delusions, but both can occur.

The good news is that at any given point in time most people with PD don't have hallucinations. In fact, psychosis in PD was rather rare before we had

good treatments for parkinsonism. The bad news is that many people with PD—probably at least half—will have hallucinations or delusions at some point along the course of their illness.



Psychotic symptoms may not bother the patient at first. For instance, one of my patients sees old friends sitting with him when he's alone and finds it comforting. But for several reasons your doctor has to know right away if psychotic symptoms develop. The first reason is that psychosis tells us that something is going very wrong in the brain, but it doesn't tell us what. It could be an intrinsic brain disease like severe depression, a major physical illness like pneumonia or an outside factor like medication side effects. Some of those are emergencies and others require a change in the antiparkinsonian medication strategy. The second reason your doctor needs to know about even mild hallucinations is that they tend to worsen over time, so at a minimum their

continued on page 12



Putting for Success – Another Perfect Round!

This year's 18th Annual APDA Golf Classic in memory of Jack Buck, held on May 16, 2016, was our most successful fundraiser ever, raising \$140,500

for patient services and Parkinson research. The event, with the generous assistance of Honorary Chair John Mozeliak and Auctioneer & Emcee Tom Ackerman, also served to increase the awareness of Parkinson's in our local community. Even the rain and cold weather couldn't dampen our spirits and it ended up being a great day for golfing at Algonquin Golf Club!

Our success was attributed to our loyal sponsors: **MASTERS** level sponsor: Carol House Furniture; **MAJOR** level sponsors: Luxco, Moneta Group, Selequity, Teva Pharmaceuticals and Wells Fargo; **GOLF CART** sponsors: Fairlie Law, LLC and Ogletree Deakins; **CONTEST** sponsors: Benton Homebuilders Community Partnership, BJC HealthCare, Enterprise Bank & Trust, Guarantee Electrical, KPMG and Riverside Furniture; **LUNCH** sponsors: Suzanne & Dave Spence and Scottrade; **COCKTAIL RECEPTION** sponsors: Budget Billboards, Inc./ For Pete's Sake, Delta Dental of Missouri, Ted Hume, Lynn & Steve Hurster, and S.E. Farris Law Firm and the St. Louis Cardinals; **BEVERAGE/ SNACK** sponsors: Jean & John Basilio, Centric Group, Fastsigns of Bridgeton, Gershman Commercial Real Estate and Stonecrest Senior Living; **DRIVING RANGE** sponsor: Cushman & Wakefield; **PRACTICE GREEN** sponsors: Dowd & Bennett and Jack Strosnider; and **HOLE** sponsors: Ameren, Don Carlson, Sonya & Larry Davis, The Delmar Gardens Family, Henges Interiors, Husch Blackwell, LLP, Kodner Gallery, Merrill Lynch, Midland States Bank, Petro-Mart/Western Oil, Inc., Shillington Box Company, Weintraub Advertising and Zeigler Associates Business Printing. Our **EXCLUSIVE MEDIA SPONSOR** KMOX allowed us to market and promote the golf tournament, which also helped raise awareness of the APDA and Parkinson disease.

CHARITABLE CONTRIBUTIONS arrived in generous proportions from Joe Buck, Cratex Corporation, Sonya & Larry

Davis, Debbie & Karl Guyer, Horner & Shifrin, Inc., Sharyn & Ron Kessler, Kelly & Matt LaMartina, Elissa & Joe Marchbein, Reitz & Jens, Inc., Alice & Bert Schott, Jennifer & Robert Schuller and Suzanne Wood.

AUCTION ITEMS were donated by Tom Ackerman, Algonquin Golf Club, Annie Gunn's, Beaver Lake Duck Club, Bootheel Outfitters, Crooked Slough Hunt Club, Stacy & Carol Hastie, Kyle D. Lucks, Carolyn & Chris McKee, Mister Guy Clothiers, Dan O'Grady, and the St. Louis Cardinals.

Caps off to these special **VENDORS** who helped make the event a success: **Autohaus BMW** for the hole-in-one car; **Fastsigns of Bridgeton (Barry Roufa)** for the wonderful signage and pin flags; **Stonecrest at Clayton View** for the golf towels; **Golf Discount** for the goody bags; **Charles Barnes, Zach Dalin and Bryan Schraier** for their professional photography

services; **Pretzel Boy's** and the **St. Louis Cardinals Tom Ackerman, Dan McLaughlin &**

John Mozeliak for media/marketing leading up to the sold-out event. Dennis Pugh one of our Chapter members with Parkinson's, entertained the crowd with his light-hearted humor, while also speaking about his experiences with PD, the APDA Greater St. Louis Chapter and his optimism



Above: Dennis & Rilla Pugh and Bill Billings



Below: Marilyn Warren and Sandy Steppig



Tom Ackerman & John Mozeliak

for the future. Dr. Perlmutter, the Medical Director of the Greater St. Louis APDA, Head of the Movement Disorders Section and a distinguished Movement Disorder Specialist at Washington University, shared with our golfers and dinner guests some of the great work that he and his fellow movement disorders specialists are doing, as well as the hopefulness he feels as a scientist working to find causes and a cure for this disease. He also expressed his gratitude for the generosity and support provided as a result of this fundraising event. As a result of Dennis' inspiring story and Dr. Perlmutter's research update,

over \$27,000 was collected during the **Fund-a-Need** portion of the evening from the charitable individuals/couples present: Dennis Barnes, Sr., John Basilico, Dave Butler, Rich Chrismer, Gerry Clark, Ann Cook, Glenn Davis, Harold Denlow, Jim Edwards, Jason Flower, Conrad Franey, Paul Gallant, Rachel Giffhorn, Paul Hatfield, Chris Hirth, John Hogan, Gil Hoskins, Frank Janoski, Chris Kuseliauskas, Jim Lally, Mark Lawson, Alan Lemley, Nancy Lieberman, John Martin, Jason Morris, John Mozeliak, Janet Noble, Steve Ostrander, Bill Reller, Vic Richey, Paul Ross, Jr., Dave Sadler, Bob Sanderson, Kevin Schoen, Kathy & Doug Schroeder, Annemarie & Matt Schumacher, Rich Schumacher, Mike Schumacher, Rich Smith, Sandy Steppig, Paul Vandivort, Bob Warren, Bill Warren, Greg Williams and Marty Zygmund.

We can't forget to thank our **142 golfers** who had a great day on the greens, bidding on many wonderful auction items, enjoying the question-and-answer session with John Mozeliak and Tom Ackerman, and feasting on the dinner served by wait staff at Algonquin. Auctioneer-extraordinaire Tom Ackerman secured bids for our **one-of-a-kind** live auction items including a unique, signed painting of St. Louis Cardinals great Adam Wainwright, by Kyle D. Lucks; the pair of signed jerseys from Cardinals players Stephen Piscotty and Seung Hwan Oh; a party suite for 43 people at a Cardinals game; a dinner for six with Chris Kerber and John Kelly at Annie Gunn's; an in-studio visit to Sports Open Line and dinner with Tom Ackerman at Zydeco Blues; an opportunity to hit the links in style with a \$500 gift card to Mister Guy Clothiers, plus lunch and a golfing outing at Algonquin Golf Club; dinner



Above: Rich Schumacher, Annemarie & Matt Schumacher (co-chairs)

Below: Debbie Guyer and Steve Hurster

for four at Element followed by an evening with the band Chicago at Peabody Opera House; and a waterfowl hunting package including hunts for two at Crooked Slough Hunt Club, Bootheel Outfitters and Beaver Lake Duck Club. It does indeed "take a village" – special recognition to our hard-working **volunteers** under the direction of Golf Committee Co-Chairs, Matt & Annemarie Schumacher, and committee members Matt LaMartina, Mark

Lawson, Alan Lemley, Barry Roufa, Dave Sadler, and Chris Vinyard; as well as Terri Adams, John Basilico, Rebecca Bruchhauser-Farris, Ann Cook, Tricia Creel, Linda & Eddie Dahl, Brian Hantsbarger, Ashley Kichura, Nick Krumbholz, Gabrielle Mack, Annie Marshall, Craig Miller, Elena Nunez, Lauren Potje, Tara Sanders, Nancy Schillinger, Rich Schumacher, Matt Specter, Amy Thomas and Marilyn Warren. A big thank you to our tireless **volunteers from Scottrade** who spent the day with us as part of their community day of service: Drew Achter, Isaac Benrubi, Lizzie Curry, Scott Deters, Moses Jaoko, Dave Lucido, Mary Lou Sullivan, Jen Summers and Matt Weaver.

If you are interested in volunteering to join our golf committee, or **if** you wish to receive an invitation for next year's golf tournament to be held on Monday, **May 15, 2017**, at Algonquin Golf Club, let us know by phone: 636.778.3377 or e-mail: info@stlapda.org. ■



Photos reprinted with permission from Ladue News

Parkinson Plus Syndromes-MSA, PSP, CBS, Vascular Parkinsonism

Joel S. Perlmutter, MD, Medical Director of the Greater St. Louis APDA, APDA Center for Advanced PD Research at Washington University, and Head of Movement Disorders Section at Washington University School of Medicine

About 20% of people with parkinsonism have a Parkinson Plus Syndrome (PDplus) rather than idiopathic Parkinson disease (iPD). One must first understand the notion of parkinsonism to have a good sense of PDplus. Parkinsonism refers to a constellation of clinical manifestations that may include slowness, stiffness, tremor, poor postural stability, shuffling gait, soft speech and difficulty swallowing. The most common cause of parkinsonism is iPD, which has rather specific changes in the brain including abnormal deposits of a protein alpha-synuclein in nerve cell, loss of nerve cells that make the chemical messenger dopamine and additional changes in other brain neurotransmitters. iPD may itself have several different causes. A definitive diagnosis of iPD requires examination of the brain after death, although multiple clinical clues permit PD experts to be fairly accurate in clinical diagnosis, particularly after many years of follow-up.

Parkinsonism also characterizes the PDplus syndromes. These other progressive neurologic conditions listed in order of relative frequency include disorders such as **Multiple Systems Atrophy (MSA)**, **Progressive Supranuclear Palsy (PSP)**, **Corticobasal Syndrome (CBS)** and **vascular parkinsonism**. Each of these may have clinical clues suggesting that

the parkinsonism is not due to iPD. The most common clues are falling in the first year of the disease and lack of response to reasonable doses of levodopa, but this alone does not completely distinguish iPD from PDplus syndromes. For example, **MSA** and **PSP** may respond to this medication and do so for several years; however, the degree of response (if it responds at all) and continued long-term benefit, is usually far less in

catheterization), a wide-based stance and possibly more severe freezing of gait (sudden stopping of movement) that does not respond to levodopa. Abnormal alpha-synuclein in the brain also occurs in **MSA**, but in this case the alpha synuclein is not in nerve cells but rather in different brain cells called glia.

PSP also may initially appear like iPD, but other features like difficulty moving the eyes, particularly down, can lead to early falling when walking down steps; marked stiffness of the neck; more severe reduction of eye blinking and early problems with concentration and thinking. Abnormal brain deposits of a protein called tau occur in people with **PSP**. Some have thought that **PSP** and **MSA** are more likely to affect both sides of the body equally compared to iPD that may tend to be more asymmetric, but more recent studies cast doubt on this distinction.

CBS, sometimes called **CBD** for corticobasal disease, includes

parkinsonian features but may also have sudden jerks of an arm, known as myoclonus; unusual sustained postures of the hand or foot known as dystonia; trouble with eye movements similar to **PSP**, and occasionally a weird manifestation with a wandering hand or arm that the person does not really notice. This is called “alien limb syndrome” since the limb seems alien and working on

MSA?
CBS?
PSP?
VASCULAR PARKINSONISM?

these PDplus syndromes.

Now let me briefly review each of these PDplus syndromes. **MSA** typically has symptoms similar to iPD but may also have more severe difficulty with dropping blood pressure on standing (orthostatic hypotension), much more severe bladder problems (including the need for bladder

Cocktails & CONVERSATION



It is a time to learn, a time to hope and a time to give. This year, we will be combining our fundraising needs with an opportunity to hear from a best-seller author, for a “hybrid” fall fundraising event to be held at the Ritz-Carlton on October 20. It will start at 5:00 p.m. with a cocktail reception and passed hors d’oeuvres, to be followed by a book signing and conversation with *Brain Storms* author Jon Palfreman, and culminate in a VIP dinner with Jon for our top sponsors. This will take the place of our fall fashion show and has all the elements of another successful event.

Save
the Date

Save the date for Cocktails & Conversation on October 20th at The Ritz-Carlton St. Louis. If you would like to receive more information or an invitation, call the Center at 636.778.3377 or send an email request to info@stlapda.org. We look forward to this enduring event and your participation and support.

Parkinson Plus Syndromes-MSA, PSP, CBS, Vascular Parkinsonism *continued from page 8*

its own. **CBS**, rarely, if ever, responds to levodopa. **CBS**, like **PSP**, has abnormal tau protein in the brain but some pathologic features help to distinguish these two closely related conditions.

Vascular parkinsonism may be much less common, and different PD specialists may have different notions of this. Some believe that multiple small strokes, especially in the front part of the brain, cause shuffling gait similar to iPD and refer to this condition that typically does not respond to levodopa as **vascular parkinsonism**. Others, like myself, believe that a chronic inadequate blood flow to the striatum, the part of the brain that has deficient dopamine in iPD, leads to **vascular parkinsonism**. In the early stages this condition may respond to levodopa and otherwise appear similar to iPD, but quite frankly

this is not yet a well-accepted form of vascular parkinsonism.

Overall, PDplus syndromes may progress faster than iPD, but exceptions to this faster progression are rather common. Difficulty with thinking is more common in **PSP** and **CBS** and may occur earlier in the disease course than in iPD, but again there is substantial variability in troubles with thinking in iPD. Falling within the first year of manifestations is more common in the PDplus syndromes. Despite these clues, specific diagnosis of the different PDplus syndromes can be quite challenging. Imaging of the brain with various types of scans do not convincingly distinguish these various conditions although this is a topic of much research and controversy. ■

TRIBUTES & DONATIONS 04/01/2016-06/30/2016

Tributes are a thoughtful way of expressing sympathy, giving thanks, celebrating special occasions such as birthdays, anniversaries and holidays, or honoring the memory of a loved one or friend while expressing your commitment to the Greater St. Louis Chapter of the American Parkinson Disease Association. An acknowledgement including your name (but not the amount) will be sent to the person honored or to a relative in case of memorial, and the donor will receive a prompt thank you card/letter which can be used when filing your tax return.

IN CELEBRATION OF

John Basilico on his birthday

Debbie & Karl Guyer

Joyce Brandt on her 80th birthday.

Steve & Marilyn Dardick
Essie & Earl Kessler
Joyce & Art Margulis
Sandra Spirtas

Mr. & Mrs. J. Brodsky on the marriage of their son

Mr. & Mrs. Larry Buxner

Dr. Jeff & Debbie Dalin on Jamie's engagement and Andy's graduation

Phil & Sue Schreiber

The Failoni Family – in celebration of 100 years!

Peggy & Jack Cribbin

Marilyn Goldman on her special birthday

Rochelle Popkin

Carol Goldsmith on her special birthday

Sally, Stan & Marci Zimmerman

Bob Goldsticker on his special birthday

Jeffrey & Barbara Smith

Lillian Klee on her 100th birthday

Cheryl, Harlan & Roberta

Linda Langsdorf on her birthday

Jan Abrams

Laura & Mark on their wedding

Beverly & Jerry Silverman

Susie Luten on the birth of her first grandchild

Gail & Larry Glenn

Jean & Jerry Sadler on their 50th anniversary

Gloria McDowell

Marcia Sloan on her birthday

Sharna Kohner

Richard Summers on his 90th birthday

John & Nancy Hitzeman

Terri & Bill Taylor on their anniversary

Roz Gad

Judy Taylor on her birthday

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Jane Hughes on her retirement

Parkway South High School

Marvin Marion for a speedy recovery

Pam & Jerry Brown

Drs. Scott Norris, Mwiza Ushe & Brent Wright—for a great PEP presentation.

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Drs. Ari & Adam Stein on the birth of their daughter, Rosie.

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severity has to be monitored carefully. Some hallucinations or delusions can prompt quite dangerous behavior. The third reason is that we have effective treatments for psychosis in PD.

In fact, often we can get rid of psychotic symptoms in PD. First we make sure there is no other, more urgent problem like pneumonia or severe depression. Talking to and examining the patient usually clears that up, but sometimes blood work, a urine sample, or other tests may be needed. The second step in treatment is to eliminate unnecessary medications that affect the brain, including some herbal supplements. Next, we tune the antiparkinsonian medications. Usually patients with hallucinations need to be off of medications like trihexyphenidyl or amantadine. We also try to switch the patient to levodopa rather than dopamine agonists, because levodopa has a lower risk of hallucinations for the same amount of benefit on movement. Finally, we reduce the dose of antiparkinsonian medications, if we can do that without causing more problems.

When these initial steps do not abolish the hallucinations, we add an antipsychotic medication. Until recently we had three options. (1) Older antipsychotics work, but are a bad idea in PD because they worsen the movement problems too much, sometimes dangerously so. (2) Clozapine clearly works, doesn't worsen PD movement symptoms substantially, and is the right choice for many patients. However, patients on clozapine must have

frequent blood draws (weekly at first, eventually down to once a month). This is because one or two people in 100 will have a potentially lethal side effect. The blood draws are meant to detect that before it gets serious. (3) There are several newer antipsychotic medications; the best-known example in the PD world is quetiapine. It is well tolerated at the low doses used in PD, and most experts believe it helps some patients. Unfortunately, none of four controlled studies in PD could prove quetiapine to be any more effective than a placebo (sugar pill). Since 2008 the label for all these antipsychotics has carried a prominent ("boxed") warning that "elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death."

Recently there has been excitement about a new medication, pimavanserin. At the beginning of this decade, 199 PD patients with psychosis volunteered for a research study in which they were assigned randomly to take pimavanserin or placebo for six weeks. The results were published in 2014 and showed significantly more improvement of hallucinations and delusions with pimavanserin than with placebo, and it did not worsen parkinsonism. The most common side effects included nausea and swelling of the ankles, each in 7% of patients on pimavanserin *vs.* 2-4% of patients on placebo. In late April 2016, the FDA approved pimavanserin for treatment of psychosis in PD, under the brand name Nuplazid™, and in June 2016, it became available through a network of specialty

pharmacies. The FDA modified the boxed warning to say that the drug was not approved for dementia-related psychosis in patients who do *not* have Parkinson disease. The retail price is almost \$2,000 per month, but the company provides resources to make the drug affordable for most patients (www.nuplazid.com/connect/overview/ or 1.844.737.2223).

What makes pimavanserin different? All previously marketed antipsychotics block dopamine transmission in the brain at the D2 family of dopamine receptors. I think of them as "anti-amphetamine" drugs, since amphetamine makes the brain release dopamine (and norepinephrine). Pimavanserin is an entirely different kind of medication. It reduces activity at serotonin 5HT2A receptors. I think of it as an "anti-LSD" drug, since LSD appears to cause hallucinations by activating 5HT2A receptors. Several newer antipsychotics block 5HT2A receptors as well, but pimavanserin does not block dopamine receptors. We think that is why it does not worsen parkinsonism while all (or nearly all) other antipsychotics do. ■

Disclaimer: Acadia Pharmaceuticals, the company that makes pimavanserin, paid Washington University for research studies Dr. Black worked on, and has paid Dr. Black for advisory board and speakers bureau participation (but not for writing this article, nor did they have anything to do with the content of this article).



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OPTIMISM GOLFS Michael Meehan and the entire Meehan family from Belleville, IL, hosted the first annual golf tournament benefiting the Greater St. Louis APDA, which serves the state of Missouri and Southern Illinois. They raised \$9,815 – a wonderful first-year effort. They are committed to do even better next year – so stay tuned and get those clubs ready and sponsorship dollars in hand to play for APDA.

OPTIMISM GOES CASUAL for a CAUSE John Buck (spouse of Mary Buck who facilitates our Chesterfield support group) nominated the Greater St. Louis APDA as a "casual for a cause" charity for the employees of his Morgan Stanley Chesterfield branch. Their employees donated \$1,000 during their special Friday dress-down days for APDA. We applaud their efforts and commend Morgan Stanley for supporting local charities during these casual day campaigns on Fridays. Casual days and Fridays always make us smile.

Missouri Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, www.stlapda.org, or call the APDA Information & Referral Center at 636.778.3377 or the facilitator at the number listed below.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	2:00 PM	Gayle Truesdell	636.923.2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street, Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck	636.532.6504
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard, PhD	636.778.3377
Columbia*	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton	573.356.6036 573.434.4569
Creve Coeur	St. Louis	Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl. CLI Rm. 419	3rd Tuesday	6:30 PM	Joe Vernon	314.614.0182
Creve Coeur	St. Louis	Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl., CLI Rm. 419	3rd Tuesday	6:30 PM	Doug Schroeder	314.306.4516
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Laura Sobba	636.931.7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314.869.5296
Jefferson City	Cole	Capital Region Medical Center Community Conference Room	3rd Friday	1:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Every Monday	3:00 PM	Nancy Dunaway	417.556.8760
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816.861.4700 x56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW Patty Waller	314.286.2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314.372.2369
Lake Ozark*	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy & David Dalton	573.356.6036 573.434.4569
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	573.201.7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314.846.5919
South City St. Louis*	St. Louis	Cure PSP Group - St. Louis Altenheim 5408 South Broadway St. Louis, MO 63111	4th Friday	11:00 AM	Beth Evans	314.732.3433
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	2nd Thursday	2:00 PM	Valerie Givens, RN	417.820.3157
Springfield*	Greene	Parkinson's Caregivers Support Group Meyer Orthopedic and Rehabilitation Hospital 3535 S National Ave. Administrative Classroom	1st Wednesday	5:00 PM		417.269.3616
Springfield*	Greene	Parkinson's Young Onset Support Group Cox Medical Center 1423 N Jefferson Ave Meyer Center Conference Room C	4th Thursday	7:00 PM		417.269.3616



continued from previous page

Missouri Support Group Calendar

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Springfield*	Greene	Parkinson's Senior Support Group Cox Medical Center 1423 N Jefferson Ave Meyer Center Conference Room C	Last Wednesday	2:30 PM		417.269.3616
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Groomes, RN	636.926.3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573.543.2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283 660.485.6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314.713.4820
Webster Groves	St. Louis	Bethesda Orchard - Parlor Room 21 North Old Orchard Ave.	Last Friday	10:30 AM	Laurel Willis, MSG	314.373.7036
Webster Groves	St. Louis	Laclede Groves 723 S. Laclede Station Rd.	3rd Wednesday	3:00 PM	Shawn Riley	314.446.2452



Illinois Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, www.stlapda.org, or call the APDA Information & Referral Center at 636.778.3377 or the facilitator at the number listed below.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Alton	Madison	Senior Services Plus 2603 N. Rodgers Ave.	2nd Tuesday	9:30 AM	Britney Di Ulio	618.465.3298 x120
Belleville	St. Clair	Southwestern Illinois College Programs and Services for Older Persons 201 N. Church St.	2nd Monday	1:30 PM	Jodi Gardner, MSW, LCSW	618.234.4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, MD	618.549.7507
Centralia	Marion	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Betty Evans Helena Quaid	618.533.0224 618.493.6064
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Road	Every Monday	10:00 AM	Charles Rohn Chuck Arbuckle	217.549.6167 217.586.3100
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Nancy Goodson Mary DeLong Rich Rogier	618.670.7707 618.288.3297
Greenville	Bond	Bond County Sr. Center 1001 E. Harris Ave.	4th Monday	10:30 AM	Anna Oestreich	618.664.1465
Greenville	Bond	Bond County Sr. Center Baumberger Comm. Rm. CAREGIVERS ONLY	4th Friday	1:00 PM	Anna Oestreich	618.664.1465
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut—Meeting Room 2	1st Wednesday March-December	6:00 PM	Karen Ladd	217.377.4973
Mattoon	Coles	Odd Fellow-Rebekah Home 201 Lafayette Ave.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217.268.4428
McLeansboro	Hamilton	Heritage Woods – Fox Meadows 605 S. Marshall Ave., Dining Room	1st Wednesday	1:00 PM	Paula K. Mason	618.643.3868
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	3rd Sunday Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.483.4300
Quincy	Adams	Quincy Public Library 526 Jersey St.	1st or 2nd Saturday- Please contact leader	10:30 AM	Terri and Dave May	217.224.7027



Exercise Classes

The APDA now offers 17 exercise classes that meet weekly. Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our patient services funding comes from donations and is limited, so we encourage those who wish to attend multiple classes to make a \$5 per week donation. This minimal donation helps us defray the cost of the classes which run around \$10 per person to cover the instructors' salaries, room rentals, and equipment. This donation request is on an honor system, and we don't turn anyone away from attending as many classes as they choose. To make a donation for exercise

classes, use the envelope in your newsletter and note that it is for exercise class. Many people choose to pay quarterly to reduce the number of checks they write each month. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our community.

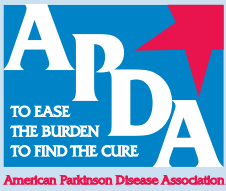
Our exercise classes meet once a week or otherwise as noted. Attend one class per week at no charge, or for \$20/month attend as many classes as you want. No RSVPs are required. Check our website, www.stlapda.org, or call 636.778.3377 to find out any changes since publication.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Chesterfield	St. Louis	St. Luke's Deslodge Outpatient Center 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Sarah Farnell, OT	314.205.6934
Chesterfield	St. Louis	Friendship Village 15201 Olive Blvd. Friendship Hall-Door #5	Tuesday	1:30 PM	Hannah Forsythe	636.733.0180 x7719
Chesterfield	St. Louis	Parkinson Resource Center 1415 Elbridge Payne, Ste. 150	Monday	1:30-2:15 PM Seated Class 2:30-3:30 PM Standing Class	Tricia Creel, DPT	636.778.3377
Chesterfield	St. Louis	Tai Chi Parkinson Resource Center 1415 Elbridge Payne, Suite 150	Wednesday Thursday Friday	Intermediate- 10:00 AM Advanced- 12:30 PM Beginning- 11:30 AM	Craig Miller	636.778.3377
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Thursday	10:00 AM	Nancy Robb	314.869.5296
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Monday	2:15 PM	Nancy Dunaway	417.781.2727
Kirkwood	St. Louis	RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear	Thursday	1:00 PM	Hannah Forsythe	314.822.6825
Ladue	St. Louis	Tremble Clefs Singing Salem United Methodist 1200 S. Lindbergh Blvd. Lower Level Choir Room	Saturday	1:30 PM	Linda McNair, MT-BC	636.778.3377
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle	Tuesday Friday (New Participants)	11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Summer Session July 5 - Sept. 12 Fall Session Oct. 3 - Dec. 9	2:00 PM Thursdays	Kathleen	636.896.0999 x21
Greenville, IL	Bond	Bond County Sr. Center 1001 E. Harris Ave.	Wednesday	10:30 AM	Anna Oestreich	618.664.1465

*denotes non-affiliated APDA support group

Do you have questions related to Parkinson disease and exercise? Please call the APDA National Rehabilitation Resource Center at Boston University - toll free helpline to speak with a licensed physical therapist who can answer your questions about exercise and identify exercise and therapy resources in your area.

TOLL FREE NUMBER: 888-606-1688 or Email at rehab@bu.edu



American Parkinson Disease Association
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Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list or if you'd rather receive an electronic version. Just call **636.778.3377** or email info@stlapda.org to let us know! Thank you in advance for helping us spend our resources wisely!

Check out our Facebook page at www.facebook.com/APDAGreaterStLouisChapter



Remember to use your eScrip card every time you check out at Schnucks grocery stores and earn dollars for APDA Greater St. Louis Chapter!



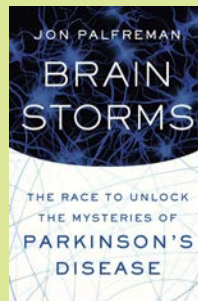
August 20, 2016 - Hull of a Race, Hull, IL August 20 will mark the 11th year for this annual event, which began under the direction of Quincy, IL APDA Parkinson support group facilitator Lori and continues as a tribute to Marilyn White, a beloved retired teacher who has Parkinson disease. Both 5K and 10K race courses are certified and professionally timed. The race is followed by the Hull Picnic & Chicken Dinner. You can register online, by mail or the morning of the race. Pre-registration is preferred. Registration opens at 7 a.m. on race day. Visit the website, www.hullofarace.com for more details and join their efforts to exceed the \$10,000 the Hull group contributes to the APDA annually.

August 27, 2016 – A Battle of the Decades 80s vs. 90s Trivia Throwdown sponsored by Stonecrest at Clayton View with all proceeds benefiting the Greater St. Louis APDA Chapter. For questions or to RSVP, contact Rachel at 314.961.1700



September 20-23, 2016 – 4th World Parkinson Congress in Portland, OR Join others from St. Louis in Portland, OR, for the 4th World Parkinson Congress (WPC). The

WPC is held every three years and provides an international forum for learning about and discussing the latest scientific discoveries, medical practices and initiatives related to Parkinson disease. To learn more or to register, go to www.WorldPDCoalition.org.



October 20, 2016 – Fall Fundraising Event- Cocktails and Conversation, to be held at the Ritz-Carlton. Jon Palfreman, author of the best-seller *Brain Storms*, joins us at a cocktail reception, talk and book signing. To receive an invitation or sponsorship information on this event, please contact the Center at 636.778.3377 or send an email to info@stlapda.org and your name will be included on the invitation list.



November 6, 2016 – Doctor in the House Dr. Joel Perlmutter answers questions about Parkinson disease as well as highlights some of the year's exciting developments and findings in search of causes and a cure. Our fall PEP meeting is sponsored by the JCA Charitable Foundation and will be held at **Congregation B'nai Amoona at 324 S. Mason Rd., in Creve Coeur.**