PARKINSON'S LiNK

MAY 2016
Volume 30, Issue 2

Newsletter of the American Parkinson Disease Association
Greater St. Louis Chapter

Serving Missouri and Southern Illinois

IN THIS ISSUE

TO EASE
THE BURDEN
TO FIND THE CURE

American Parkinson Disease Association

APDA Greater St. Louis Chapter
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Check out our Facebook page at www.facebook.com/APDAGreaterStLouisChapter

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.

Telling Others You Have Parkinson Disease

By Terri Hosto, MSW, LCSW

If you have recently been diagnosed with Parkinson disease (PD), your diagnosis will affect not only you but also your family members, friends and others who are close to you, such as coworkers. Telling others about your illness may seem uncomfortable at first. You may worry about how they will react to the news. Will it upset family members or cause them undue worry? Will friends treat you differently even if unintentionally? Will coworkers continue to value your input? Will people drift out of your life because they feel uncomfortable being around you?

When the time seems right for you to reveal your PD diagnosis to others, you will need to think about what information you want to share and with whom. What do others need to know about PD and the particular symptoms you have? How many personal details should you share? While you may feel hesitant and awkward talking about your situation, being up front and open about it may save you a lot of excuses and explanations for difficulties you may be experiencing.

There is no one right way to tell others about your diagnosis; just be yourself and be honest. Keep it simple. For example, describe your symptoms and how the diagnosis was made. Talk about how it affects your everyday life. Use this opportunity to inform and educate your loved ones about PD—even as you, too, are learning about the disease. Tell them it is a brain disease that causes trembling or shaking, stiffness, slowness in movement and thought, and trouble walking. Explain that PD affects each person differently, there is no way to determine exactly how the disease will unfold, and that you are learning how to cope with it. Discuss how your symptoms are being managed by medications and exercise, and talk about what they can do to help you.

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Telling Others You Have Parkinson Disease

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Encourage them to ask questions. Consider sharing informational materials with them or inviting them to attend educational programs and support groups provided by the APDA. The more they learn about the disease, the more comfortable they will feel being around you.

You may find that the benefits of telling others about your diagnosis outweigh many of your worries. Some symptoms of PD are hard to keep secret. Family members, close friends and even coworkers may have been wondering what's going on. Telling them about your illness allows you to give them true and accurate information while deterring false assumptions. You no longer need to be discreet about medical appointments or make excuses for why you sometimes have trouble walking or keeping your balance. Talking about it also allows you to openly discuss health care decisions and make plans for the future. Updating your will, making advance directives, appointing powers of attorney and reviewing long-range financial plans can be constructive and affirming for both you and your family.

If you are working, it is important to know that you are not required to disclose your medical condition to your employer unless you decide to ask for special accommodations for your job or job setting. The primary factor to consider is whether your illness affects your ability to perform essential job functions. If you believe that it does, then you should first think about what specific accommodations you will need to ask for in order to do your work. Reasonable accommodations may include adaptations to the work environment as well as restructuring your job responsibilities, allowing a flexible or modified work schedule, temporary light duty assignments or unpaid leave.

Next, make a plan to discuss your condition with your employer. Only share information that is related to your job and your work setting. Do it in a straightforward way. Describe specific job limitations that are caused by your illness. For example, you may request taking short breaks during the work day if you experience fatigue because of your PD. Be sure to also talk about your work experience and positive qualities that enhance your ability to perform your job. Many employers are supportive and will have constructive ideas about making accommodations to help you continue to be successful in your job. Healthcare professionals, such as occupational therapists or social workers are trained to help you determine what accommodations you may need and help you disclose and discuss these accommodations with your employer. Stay tuned for more information in our August 2016 *LiNK* on this topic.

Although you are not required to disclose your medical condition to your employer, you may still find that there are other relevant reasons for doing so. For example, it takes away the stress of trying to cover up or compensate for difficulties caused by your illness or by side-effects from your medications. Additionally, if you should ever need medical help at your place of work, it may be better that a supervisor or a few close coworkers are aware of your condition and what symptoms to watch for. Telling your employer about your condition will show respect for your employer and accountability toward your job responsibilities. In turn, your employer will likely respect you for your honesty and trustworthiness.

All in all, others will treat your PD the way you do. They will look to you for help in understanding your symptoms and how they can be supportive and helpful. Be positive and upbeat and they will, too! ■

The Right Type and Amount of Exercise for Parkinson Disease

By Tricia Creel, DPT, NCS; Physical Therapist with SSM Physical Therapy and co-founder of MDT Education Solutions. Tricia leads two exercise classes for the St. Louis APDA.

As the disease progresses, many people with Parkinson disease (PD) face increasing difficulty with everyday mobility, including walking, turning to sit and getting out of bed. This can lead to loss of independence, falls and/or fear of falls and inactivity. While there is no cure for Parkinson disease, many people find that exercise and mobility training can help. Research shows that many types of exercise can help improve the symptoms of Parkinson disease and that an exercise program should be started immediately upon diagnosis.

For many years, exercise was not a recommended strategy for people with a diagnosis of Parkinson disease. However, a growing body of research now suggests that non-pharmacological approaches, including exercise, have a far greater effect on the symptoms and progression of PD than previously believed. In one recent review of the research, J. Eric Ahlskog, PhD, MD, of the Mayo Clinic, reports on accumulating evidence that ongoing vigorous exercise may have a neuroprotective effect in PD. In fact, people who exercise during their midlife have a reduced risk of developing PD later in life.

It is well established that exercise has general health benefits, including improvement of cardiovascular and cerebrovascular health, reduction of osteoporosis/fracture risk and age-related muscle loss, improvement of psychological state and perhaps even a general anti-inflammatory effect. In addition, there are numerous benefits that are specific to people with PD, such as cognitive improvements in physically fit people with PD compared to unfit people with PD.

Conversely, physical inactivity may contribute to motor deterioration and acceleration of disease progression. Results from studies completed in animal models provide compelling evidence that restricting activity, especially in the more impaired limbs, triggers increased degeneration of dopaminergic systems.

Often people with PD do not request a referral to physical therapy or do not ask their doctor how much and what type of exercise they should be doing. It can be confusing to understand which type of exercise is optimal for you and how often you need to be exercising.

So, at what intensity should you exercise? And what type of exercise should you do? The research hasn't yet given us exact answers. We still need large, well-designed, randomized controlled trials to establish the impact of different doses of a range of exercise types on the long-term impairments of individuals with PD. But here is what you can take away from the research that has already been completed:

1. *People with PD have a wide variety of symptoms, differing rates of disease progression and different mobility levels. As a result, exercise programs should be tailored to the individual. A physical therapist can help you design a tailored exercise program.*

2. *People with PD need to develop long-term, sustainable exercise habits. Even the most advantageous exercise program is helpful only if you stick with it. Find something you enjoy!*

3. *Try to participate in a variety of exercises. Group classes, especially those designed specifically for people with PD, can help you achieve this.*

4. *Challenge yourself to perform complex (multi-step or multi-task) exercises. For example, both boxing and dance-based exercise require coordination, concentration, and balance.*

5. *Include exercise that provides a cardiovascular challenge. On a scale of 0-10, with 0 representing no exertion and 10 representing your maximum level of exertion, try to reach an exertion level of 5-7.*

6. *If there is something specific that you are having trouble doing, such as turns or rolling in bed, find an exercise that mimics that activity as closely as possible. Specificity of training matters!*

To achieve the full benefits of exercise and improve your mobility, exercise for people with Parkinson disease

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Needed: New Parkinson's Vocabulary

By Peter Dunlap-Sholh

Learning to Speak Parkinson's

My Degeneration - Reprinted with permission from the author

One of the less noticed challenges of Parkinson Disease is mastering the arcane vocabulary that describes the particulars of the disorder. If we want to speak clearly with our doctors and others about what ails us, we have to use strange words like "dyskinesia," "festination," "dystonia," and "bradyphrenia." Words that are fun to say on their own, but even more fun to rattle off as part of a sentence. "In spite of severe dystonia, she managed to festinate across the room."

I like showing off my vocabulary as much as the next person, (ok- I like it even more than the next person) but why do the doctors get to have all the fun making up the words? Plus, there are many word-worthy phenomena related to PD that they have overlooked! Who controls language controls how we think about about whatever it is we are talking about. Time for a little patient empowerment.

With that in mind, I offer some new PD words for us to consider adding to the current store.

"Pinballing" this one was coined by my wife to describe the tendency I and other people with PD have to walk erratically, knocking into shelves, signposts, and one another as we lurch through life.

"Bladderdash" adapted from the free-wheeling speech of Alaska Rep. Don Young, describes the desperate process of finding a bathroom, frantically fumbling to unbutton and unzip your pants, and whipping down your underwear in time (you hope) to empty your urgent bladder.

A **"Murmur"** of PD patients. A collective noun for a bunch of people with PD.

"Parkanoia" the feeling that people are covertly observing your PD symptoms. And judging you for them.

"No Parking Area" A place or circumstance where you feel uncomfortable exhibiting Parkinson's symptoms, like in a restaurant, on a plane, in a park, at school, in church, at the grocery store, in a barber shop, on the subway, at a movie, attending a concert, at work, in the gym, at the library, buying shoes, on a date, at the pool, in court, at the ball game, in a bar, at a museum, with your neurologist, etc… etc… etc…

"Depillitated" Caught without access to your pills when you need them.

"Repillitated" To have access to your pills restored.

"Ghost Dose" Skipping a pill by accident, then grinding to a halt.

"Parkinstoned" To appear to be drunk or high due to PD symptoms such as lurching, falling, and slurred speech.

"**Dopameanie"** A perfectly nice person with Parkinson disease who is mistaken for an anti-social jerk because they don't smile due to facial muscle freezing.

"Parkinspotting" The habit of mentally diagnosing random strangers who lack arm-swing, have soft, hoarse voices, and/or walk slowly, but are clueless about the tell-tale symptoms of PD they are exhibiting.

Think how much easier these new words will make life. When someone asks what you did today you can say "I went to the mall to do a little Parkinspotting, and suddenly realized I had ghost-dosed my last pill. Wouldn't you know, I was depillitated, I'd left them on the nightstand at home. Naturally parkanoia kicked in, and on top of that, I had to bladderdash to the restroom. Of course, by then I was totally parkinstoned and pin-balling all over the place. Security eventually threw me out, but I've been repillitated, and I'm fine now, except for a few bruises."

See how easy and fun that is? (A little something to make you smile!) ■

Reprinted with permission from the author, Peter Dunlap-Sholh, NPF Blogger and NWPF. The article originally appeared on the nwpf.org website PD Community Blog on Friday February 26, 2016. You may link directly to their website using the link: https://nwpf.org/stay-informed/blog/2016/02/needed-new-parkinsons-vocabulary/

Affording Your Medication May Be Easier Than You Think!

Deborah Guyer, MA, Executive Director, Greater St. Louis APDA Chapter

I recently became knowledgeable about an organization created to advocate on **your** behalf.

Rx Outreach is a nonprofit pharmacy based in St. Louis, which serves all 50 states. Their mission is to provide affordable medication for people in need by helping to fill the gap that too often occurs AFTER the search for free medication has been exhausted and BEFORE people are forced to consider a retail solution or are simply discouraged. Rx Outreach offers many drugs for a fraction of the price of retail or for free.

In these times of rising drug prices, confusing healthcare coverage and uncertainty, this affordable medication program sounds almost too good to be true. It sounded that way to me when I was first introduced to Rx Outreach. Rx Outreach publishes all prices (available online or by request) for the medication needed. There are NO additional or hidden fees. NO membership fees, NO enrollment fees and NO standard shipping and handling fees.

To help in your search for affordable medication, consider the following tips to reduce the overall cost of your medication:

- Exhaust every opportunity to get your medication for free.
- Patient Assistance Programs (PAPs) are available for people with low incomes for many brand name medications through the individual medication manufacturer.
- Samples may be available through your doctor.
- When free medications are no longer available or an option, use a sustainable pharmacy source for your medication.
- Shop around and ask questions. No one source will have the lowest price every time. However, using a pharmacy source that is sustainable (stable/consistent) over time will save you money and valuable time.
- Consider using a mail-order pharmacy for your medication needs. They have affordable prices and convenient in-home delivery.
- Make sure the pharmacy is accredited.
- Consult with your care provider.
- Request generic medications when available and 90- or 180-day prescriptions, if applicable.
- Afraid you'll reach the "donut-hole" too quickly? Buying medications from an affordable source can save you money and help slow your approach to the donut-hole.
- If you've found a pharmacy with affordable medication, share it with your family and friends!

Rx Outreach is the nation's largest, non-profit, fully licensed, mail order pharmacy and Patient Assistance Program (PAP), offering more than 300 branded and generic medications at affordable prices or free. Julie Reed, Chief Development Officer in Pharma Relations, at Rx Outreach has evaluated a number of medications used by individuals with Parkinson's to add to their formulary. It may be worthwhile to check to see if the drugs you take have been included in their expanding list of pharmaceuticals. For more information, call 1-888-RXO-1234 or visit their website www.rxoutreach.org. ■

American Parkinson's
OPTIMISM
EVENTS

OPTIMISM PLAYS…TRIVIA

You may recall that the St. Louis Esprit, now St. Louis Chaos, honors Marty Rudloff every year through their trivia night fundraiser. The girls' softball team raised $750 in February 2016, bringing the total contributions for local patient services to $5,550 since this Optimism event began in 2012 for His Honor Marty Rudloff, then long-standing mayor of Bellefontaine Neighbors. Keep on sponsoring these trivia nights, which not only honor Marty, but contribute greatly to the quality of life for all of our Parkinson community, empowering them to advocate for themselves through our patient services and programs.

OPTIMISM WRITES …POETRY

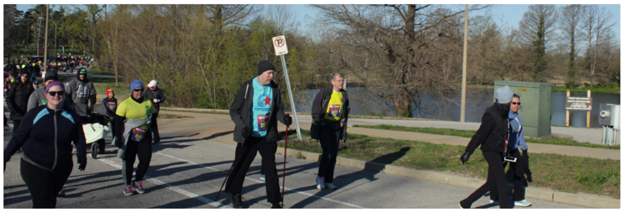
Charles Manley has written a book, *Dogged Doggerel*, which is a collection of poems, essays, and other thoughts that he has spent the last several years composing. He has donated all of the sales of this book to the St. Louis Chapter of the American Parkinson Disease Association. Kimberly Perry, Charles' spouse, constant companion and devoted care partner, explained that Charles, a pediatric urologist at Children's Hospital for 25 years, retired following his Parkinson diagnosis in 1994. He underwent DBS surgery in 2007 and is an active participant in our Tremble Clefs choir and the Clayton Exercise Classes. Charles was involved in the Tango classes and research until back surgery, which prevented him from engaging further in dance. The books are available for a minimum contribution of $20. Please contact Kimberly Perry through the Parkinson Resource Center at 636-778-3377 should you wish to purchase one. ■

On Your Mark – Get Set – GO!

During the weekend of April 9-10, the APDA Greater St. Louis chapter participated as an official charity of GO! St. Louis for the third consecutive year. Our chapter had participants in all the events during the weekend, including the mature mile, 5k, half marathon, and even a marathon runner! We were pleased to have so many people supporting the APDA through their participation and donations, which will help fund programs, patient services and research that is aligned with our mission of easing the burden and finding a cure for PD. We welcomed participation from some of our exercise classes, including the St. Peters & Clayton exercise classes, as well as our Tai Chi classes, and a record turnout both in participants and funds raised by the Tai Chi class and St. Peters exercise group, Team Tremor. We also wanted to give special mention to our top fundraising team, newcomer Fred Ferrell and his Bootheelers, who put together a team of over 25 walkers from Charleston, MO and raised $5,300! Following close behind was the Tai Chi Exercise Class led by Craig Miller, which raised $5,100, Gail Glenn, who continued her streak as a top supporter from last year by raising $5,000, and finally, Team Tremor, led by Holly Evans, which raised $2,600. We would like to thank these four captains, as well as everyone else who talked to their family, friends and neighbors to help raise money and recruit walkers!

As we think ahead to 2017, we are excited to announce that we will be moving away from the GO! St. Louis platform and will be hosting our own APDA Greater St. Louis Chapter Walk in the Park at a yet-to-be determined St. Louis County park. This change will help us make the walk more accessible to everyone within our Parkinson community, and we invite you to build a team and invite your family members, friends and neighbors! Cost will be lower, and our focus will be more on making this a true Optimism event, where we can build community and help to grow awareness of Parkinson's within the bi-state region. We are looking for committee members who will be invested in the project and invigorated to help us as we move forward into this new phase of the walk. Please continue to check our website, as we will be posting updates about our Optimism Walk as we receive them.

Our gratitude is extended to all those who have donated to or participated in this event. We hope that you will all join us again- and invite everyone you know- for our new and improved 2017 Optimism Walk! We regret that we are only able to list gifts of $50 or more, which were received by April 13, 2016. Please refer to a complete listing at https://www.crowdrise.com/apda2016. For a complete viewing of the photos captured during the weekend, visit our website at www.stlapda.org. ■



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Clinical Trials – Recruiting Participants!

Biotie Tozadenant – Parkinson Disease and Wearing Off Dr. Susan Criswell at Washington University School of Medicine is participating in a research study investigating a drug called Tozadenant for those who have Parkinson disease and are experiencing wearing-off periods between their levodopa doses. Tozadenant is an investigational drug which means that it is not approved for use in the US by the FDA and, therefore, has not been marketed in the US. To take part in the study, individuals must be between 30 and 80 years old with a diagnosis of PD and are experiencing wearing OFF from their PD medications. Participation will last approximately 1.5 years and includes up to 14 office visits. For more information, please contact Laura at 314-362-3372 or RUNDELLL@neuro.wustl.edu.

Acorda CVT 301-004 Study – Parkinson Disease and Wearing Off Dr. Susan Criswell at Washington University School of Medicine is participating in a research study investigating a drug called CVT-301 for those who have Parkinson disease and are experiencing wearing off periods between their levodopa doses. The pill form of levodopa is currently approved by the FDA for the treatment of PD symptoms. The study drug, CVT 301, is considered investigational and is levodopa in powder form. It is inhaled through an inhaler. Many PD patients take levodopa as a pill at least 4 times a day, but still experience periods of "wearing off" (called OFF episodes) between their usual doses. The primary purpose of this study is to see if the study drug CVT 301, when inhaled through an inhaler, will provide faster relief of motor fluctuations (OFF episodes) when compared to placebo (no active drug) in patients with PD.

To take part in the study, individuals must be between 30 and 85 years old with a diagnosis of PD and are experiencing wearing OFF of your PD medications. Participation will last approximately 19 weeks and includes up to 8 office visits. For more information, please contact Laura at 314-362-3372 or RUNDELLL@neuro.wustl.edu.

Istradefylline KW6002-014 Study – Parkinson Disease and Wearing OFF Dr. Susan Criswell at Washington University School of Medicine is participating in a research study investigating a medication for Parkinson disease. The purpose of this study is to test the safety and effect of an investigational study drug, istradefylline, in patients who have been optimally or maximally treated with levodopa/carbidopa therapy. KW-6002 (istradefylline) is an investigational drug which means that it is not approved for use in the United States of America (USA) by the Food and Drug Administration (FDA) and therefore has not been marketed in the U.S.

This study will test the safety and effectiveness of istradefylline to determine if it can reduce OFF time for Parkinson's disease patients with motor fluctuations and a history of dyskinesia (involuntary jerking/twisting). We want to find out what effects, good and/or bad, it has on you and your Parkinson's disease. The study is sponsored by Kyowa Hakko Kirin Pharma, Inc. (KKP).

To pre-qualify for this study, the participant must: (1) be 30 years old or older, (2) be diagnosed with idiopathic Parkinson disease, (3) be taking levodopa for at least 1 year, (4) be experiencing wearing OFF of PD medications, (5) have no history of Deep Brain Stimulation (DBS), and (6) smoke fewer than 5 cigarettes per day (if smoke at all). *Additional criteria apply*

Participation will last approximately 18 weeks and includes 7 office visits. Compensation is provided. For more information, please contact Laura at 314-362-3372 or RUNDELLL@neuro.wustl.edu. ■

The Right Type and Amount of Exercise for Parkinson Disease

continued from page 3

should be:

1. Specific to your individual impairments

2. High intensity

3. Consistent and ongoing in duration

Exercises must not focus only on balance, strength training, and flexibility, but must target overall fitness level and aim to improve cardiovascular endurance. Research has shown the benefits of multiple types of exercise, including Tai Chi, tango, tandem biking, treadmill training, boxing and pole walking. The key is to participate in a variety of exercise types, find something that you like, and stick with it. It may help to know that the terms "intense" and "vigorous" can apply to a number of aspects of exercise, including high repetition, velocity, complexity and cardiovascular response.

While the research does not prove that exercise slows PD progression, evidence for the benefits on quality of life are very compelling. However, simply advising a person with Parkinson disease to exercise is not enough. There needs to be a network of resources available to help make that happen. This includes physical therapists specifically trained to treat PD, high-quality, accessible community-based exercise programs and on-going education by physicians. The PD-specific group exercise classes offered through the St. Louis chapter of the APDA are designed to meet the principles discussed above. Listings of our exercise classes are found on our website, www.stlapda.org, and in the calendar pages of our *LiNK* newsletters. You can request a brochure on the exercise classes sponsored by the St. Louis APDA. You may also call the toll free helpline number 888-606-1688 at The APDA National Rehabilitation Center at Boston University with questions related to Parkinson disease and exercise.

And remember, it's always a good idea to consult with your physician before starting a new exercise program. ■

Is Your Sniffer Up To Snuff?

Amy Paturel, MS, MPH, is a health and nutrition writer. The following are excerpts from an article which appears in full in *Neurology Now*, September/ October 2007, Volume 3

While most people with a reduced sense of smell will not develop Parkinson's, the majority of people with Parkinson disease (PD) do have reduced sense of smell. In fact, olfactory dysfunction is among the earliest non-motor features of PD. Such dysfunction is present in approximately 90% of early-stage PD cases and can precede the onset of motor symptoms by years.

In the 1970s, researchers learned that smell is compromised in neurodegenerative conditions like Alzheimer's disease, Parkinson disease, Huntington's disease, and Multiple Sclerosis. Now they are discovering that loss of smell can be a hallmark symptom in the earliest stages of many diseases. "Recent studies of brains from Parkinson disease patients reveal structural and biochemical alterations in regions associated with the sense of smell," says Richard Doty, PhD, professor and director of the Smell & Taste Center at the University of Pennsylvania. Loss of smell occurs 90% of the time in PD. This is greater than the prevalence of tremor, a cardinal motor sign of the disorder.

Your eyes and ears may play the biggest role in getting you from place to place, but your nose plays a key supporting role. Smell can affect your life in a thousand ways. The olfactory system largely determines the flavor and palatability of foods and beverages and provides warning of spoiled foods, dangerous fumes and unhealthy environments. Of 750 consecutive patients presenting to the University of Pennsylvania Smell and Taste Center with mainly olfactory dysfunction, 68% reported altered quality of life, 46% reported changes in appetite or body weight, and 56% reported adverse influences on daily living or psychological well-being. Loss of smell – also known as anosmia – is common among those with Parkinson's. And it often shows up before better-known symptoms such as rigidity or tremors. Dr. Heiko Braak, MD, a research scientist in Germany, and many others suggest that the neural degeneration seen in PD actually begins in the gastrointestinal system and the olfactory bulb rather than the substantia nigra.

If a loss of smell is part of your Parkinson's story, you are not alone. A key element of the preclinical stage of PD is impaired olfactory function, with much of the impact on eating and taste. If you have impaired sense of smell, you can't fully appreciate and enjoy flavors in the same way. As we chew, odors ascend from the back of our mouth into our nose. Eighty percent of what we consider taste actually takes place in our noses. So if your sense of smell wanes, food may lose its allure and you may eat less. When people lose their sense of smell, it can be devastating.

Food aside, a diminished sense of smell can increase the risk of dangerous accidents around the house. Odds of hazardous mishaps are higher, including cooking accidents, sensing spoiled food, being aware of gas leaks or being able to sense smoke from a fire. Tips to offset olfactory loss include techniques to enhance and savor the flavor. Be aware of increase or decrease in your weight and let your doctor know about changes in your appetite. Opt for electric appliances instead of gas if it is feasible to do so. If you must go the gas stove route, make sure it is equipped with an automatic pilot light. Purchase sensing devices for gas. Take care when preparing food, particularly leftovers, since spoiled food can wreak havoc on your intestinal tract. Label and date all leftovers. If you're not sure if you are smelling something awry, get an opinion from someone with an intact sense of smell. Don't stop trying to use your nose. Prevent odor-related disasters! Place a smoke detector in every room that might have a fire or where people sleep, and check all alarms on a routine basis, making sure smoke alarms have batteries and work properly.

Numerous studies suggest that olfactory disturbances in PD may have diagnostic utility for the differentiation of PD from other movement disorders as well. Wenning et al. presented data suggesting that olfactory function is differentially impaired in distinct Parkinsonian syndromes. They reported a preserved or mildly impaired olfactory function to be more likely for atypical parkinsoniam such as multiple system atrophy, progressive supranuclear palsy or corticobasal degeneration whereas markedly pronounced olfactory loss appeared to suggest PD. What the nose knows! ■

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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.

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Are You Ready to Tee-Up?

The 18th annual APDA Golf Classic honoring the memory of Jack Buck will take place on May 16, 2016, at Algonquin Golf Club in Glendale, MO. Our slots for golf and the reception and dinner are filling up rapidly, so don't delay in returning your registration as this event has completely sold out for the past three years. We hope you'll join us in honoring a man whose own dauntless brand of charity has made him a civic institution in our community.

St. Louis Cardinals GM, John "Mo" Mozeliak, will serve as Honorary Chairperson. Mo's grandmother and father-in-law were diagnosed with Parkinson disease, and he remains passionate about his involvement with our cause (for which we are indebted to this St. Louis celebrity). One of the highlights of the evening is the Q-and-A session with John Mozeliak and broadcaster Tom Ackerman, which occurs prior to dinner being served. Last year, over $138,000 was raised to support our expanding patient services and programs and to fund Parkinson research. If you don't golf, there is a dinner-only option, but tickets are limited.

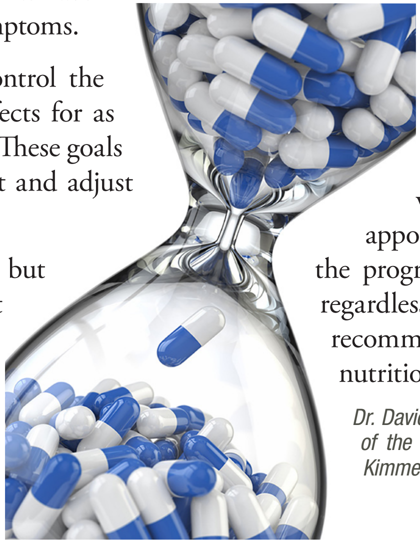
Help us honor Jack's memory with another winner! The funds generated will assist those living with Parkinson disease in our local communities as well as the researchers hard at work discovering causes and ultimately a cure for Parkinson disease. ■

When Is It Time to Start Parkinson Medication?

By David Kremens, MD

Parkinson disease (PD) occurs because the brain no longer makes enough dopamine, an important neurotransmitter (chemical messenger). The treatment options for PD all enhance or mimic dopamine in different ways to help control symptoms. Starting treatment right at diagnosis may help an individual maximize their function from the earliest stages of the disease. As the disease progresses, treatments have to be added or adjusted over time to control symptoms.

The main goals of PD treatment are to 1) control the symptoms of Parkinson's, 2) minimize side effects for as long as possible, and 3) help maintain function. These goals are important factors in deciding when to start and adjust medication.



Q. I've been diagnosed with Parkinson disease, but I'm thinking of waiting to start treatment because my symptoms are so mild. What do you recommend?

A. The decision regarding when to initiate therapy in PD has been controversial for a long time. In the past, therapy was often delayed until symptoms were bothersome and/or resulted in some type of functional impairment. But because strong evidence now suggests people who are treated for their Parkinson's disease feel better and do better than people who wait to be treated (even if they have very mild symptoms), initiating therapy at diagnosis is widely considered the preferred approach.

There are many reasons why patients consider delaying treatment, mild symptoms being one of them. Others include a desire to avoid taking medication, concerns about the expense, and worries about potential side effects. If you have any of these concerns, be sure to let your doctor know.

If my patient preferred to delay therapy, I would recommend more frequent follow-up appointments so I could keep a close watch on the progression of symptoms. And for all my patients, regardless of whether they begin treatment or wait, I recommend physical therapy and exercise, as well as good nutrition, to help with the symptoms of the disease. ■

Dr. David Kremens is an associate professor of neurology and co-director of the Parkinson Disease and Movement Disorders Center at Sidney Kimmel Medical College of Thomas Jefferson University in Philadelphia.

Brain Storms – Fall Event

Jon Palfreman, author of *Brain Storms: The Race to Unlock the Mysteries of Parkinson Disease,* will be our guest and keynote the APDA fall fundraiser on October 20.

Seven million people worldwide suffer from Parkinson's, and doctors, researchers, and patients continue to hunt for a cure. In *Brain Storms*, the award-winning television documentary producer and journalist, Jon Palfreman, tells their story, a story that became his own when he was diagnosed with the debilitating illness in 2011. Jon worked at the BBC in England and in 1985 came over to the U.S. to make an episode of the TV series *NOVA*, which led him to the story on Parkinson disease. In the documentary, he profiled a group of young drug addicts who appeared to come down with the symptoms of Parkinson disease because they had taken a bad version of a synthetic drug.

The book is Jon's journey as a journalist and as a patient to find out as much as he could about Parkinson disease. Jon has agreed to come to St. Louis in October to share his knowledge and experiences with our community. "No one wants Parkinson's. But there are many worse fates. Unlike many cancer victims, people with Parkinson's tend to survive for a long time. During this period, we (unlike our more cognitively impaired counterparts with Alzheimer's and Huntington's disease) can report lucidly on our condition until the end. Our insights can help unpack the disease and assist in the scientific pursuit of better therapies and ultimate cures. As I have learned from fellow sufferers, there are many ways to fight back against this disease," states Jon in his book.

"We know more about the human brain now than we've ever known..."

"We know more about the human brain now than we've ever known. It's an exciting time when giving money for research is likely to pay off." Jon's advice to others living with Parkinson's is valuable: *"You've got to seek a positive outlook, and you need to seek out other people with Parkinson's disease because they're an amazing source of advice. The great thing about Parkinson's disease is that you can live a long and very good life. The second thing is the value of exercise. Keeping fit and exercising is a tremendous benefit. It's within every Parkinson's disease patients hands to make the most of it."* ■

Jon will be speaking and signing copies of his book, Brain Storms, at the October 20 event. Mark your calendars for October 20, the fall fundraising event of 2016.

Sponsored by the American Parkinson Disease Association, Greater St. Louis Chapter

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 or the facilitator.

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 Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 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
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 on next page

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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 Institute 8175 Big Bend Blvd., Suite 210	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 or the facilitator.

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	Kim Campbell	618.465.3298 x146
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	Washington	Heritage Woods of Centralia 2049 E. McCord St.	2nd Tuesday	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	First General Baptist Church 708 S. 9th St.	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 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
Chesterfield	St. Louis	Yoga/Meditation Maryville University Walker Hall, Room 132 Reservations Required	Every Thursday Session Beginning Feb. 25	12:00 PM	Pradip Ghosh, PT, Phd	636.778.3377
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday	10:00 AM	Nancy Robb	314.355.6100
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	11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Spring Session April 4 - June 10 Summer Session July 5 - Sept 12	2:00 PM Thursdays	Brenda Neumann	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*

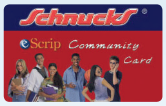
TO EASE THE BURDEN TO FIND THE CURE
American Parkinson Disease Association

American Parkinson Disease Association
1415 Elbridge Payne
Suite 150
Chesterfield, MO 63017
Address Service Requested

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!

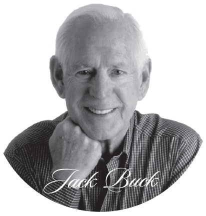
Check out our Facebook page at www.facebook.com/APDAGreaterStLouisChapter

eScrip



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

2016 EVENTS SAVE the DATE!



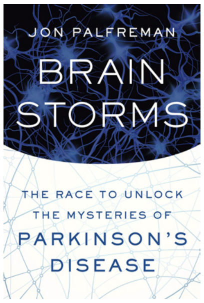
May 16, 2016 ::: 18th Annual APDA Memorial Golf Tournament honoring Jack Buck at Algonquin Golf Club. Reservations are required for golf and dinner-only option. Space is limited. Contact us at 636.778.3377 to secure your spot. John Mozeliak, GM St. Louis Cardinals, will be the Honorary Chair, and Tom Ackerman, Sports Director at KMOX Radio, will be the emcee.

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, beloved former 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.

4th World Parkinson Congress Portland 2016

September 20-23, 2016 ::: 4th World Parkinson Congress in Portland Oregon

Join others from St. Louis in Portland, Oregon, 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 Author Jon Palfreman joins us at a reception, lecture and book signing. Details on this fall fundraiser to follow.

November 6, 2016 ::: Doctor in the House. Dr. Joel Perlmutter answers questions about Parkinson disease as well as highlighting some of the year's exciting developments and findings in our hunt for causes and a cure. Our fall PEP meeting is sponsored by the JCA Charitable Foundation and will be held at Congregation B'Nai Amoona.