

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

Serving Missouri and Southern Illinois

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GREATER ST. LOUIS CHAPTER

1415 Elbridge Payne Road, Suite 150 Chesterfield, Missouri 63017 636.778.3377 | www.stlapda.org

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



And our Twitter feed at @APDAStLouis



## **OUR MISSION**

Every day, we provide the support, education, and research that will help everyone impacted by Parkinson disease live life to the fullest.

## LIVE STREAMING - EXERCISE CLASSES

TRICIA CREEL, PT, DPT, NCS, WELLNESS PROGRAM COORDINATOR-GREATER ST. LOUIS CHAPTER-APDA

eople with Parkinson disease (PD) demonstrate improvements in motor function, quality of life and balance when they participate in community exercise classes. However, many people are not able to participate because of long commutes, lack of transportation or limited

mobility. To help meet this need, we are very excited to announce live streaming of exercise classes from APDA our Community Resource Center Chesterfield. The classes are also archived for two weeks on our website, stlapda.org. Several types of classes are available

viewing via the live stream, including Tai Chi, yoga, interval training and chair-side exercise. Live streaming allows people who are not able to attend the classes in person an opportunity to participate and means that a much wider audience is reached. It also gives participants an opportunity to take the classes multiple times a week.

Research shows that half of the general population does not achieve recommended

daily levels of physical activity and that activity levels in people with PD are lower than in older adults without PD. Live streaming of Parkinson's specific exercise classes helps remove barriers and allows people to participate who might otherwise not be able to take advantage of this resource. To participate in a live streamed exercise class, visit our website at stlapda.org.

Click on Classes & Groups, then on Exercise Live Stream

> OR go directly stlapda.org/ live. Here you will

find a schedule of the live streamed classes, a link to archived classes and a section to log in to watch live streaming classes.

Of course, live streaming cannot fully take the place of attending an exercise class in person. The social aspect of attending in person is so important, as is the feedback that an instructor can provide. We recommend that

participants attend classes in person as

streamed or archived class on days when they can't attend a class in person.

much as possible, then participate in a live

LIVE

f o r

TREAM

#### **NEW CLASSES BEING OFFERED**

In addition to live streaming, we are excited to announce several **NEW** Parkinson's exercise classes in Missouri and Southern Illinois. All classes are taught by instructors who have completed advanced training in leading group exercise programs for people with PD that includes evidence-based principles for adapting exercises and safety measures to ensure that people at all mobility levels can participate.

Adapted Tango - Thursdays from 10:00 a.m. to 11:00 a.m. at Convergence Dance and Body Center in Richmond Heights, MO. Call 636.778.3377 to register. (12-week sessions)

Parkinson's Performance - Small group sessions with a personal trainer in a gym setting. Saturdays at 1:00 p.m. at the HEIGHTS in Richmond Heights, MO. Call 314.645.1476 to register. (12-week sessions) \$84 for residents and HEIGHTS members, \$108 for

#### APDA GREATER ST. LOUIS CHAPTER

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1415 Elbridge Payne Suite 150 Chesterfield, MO 63017

Hours: **7:30 a.m.- 4:00 p.m. M-F** Phone: **636.778.3377 www.stlapda.org** 

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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.

## **GROWING OLD**

DEBBIE GUYER, EXECUTIVE DIRECTOR, GREATER ST. LOUIS CHAPTER - APDA

hile watching the CBS Sunday Morning Program recently, I saw journalist Bob Schieffer interviewing the 84-year-old singer Willie Nelson. Bob asked Willie if the statement attributed to him is true: "We don't ask to get old, we just get old. And, if you're lucky, you'll get old, too." That statement made such an impression, I hopped off the treadmill so I could

jot it down to share with you in this column. Getting old and living life to the fullest is exactly what we hope for you to do.

During April, Parkinson's Awareness Month, you may notice many changes taking place. APDA has a new logo and color scheme, an updated new website and a focused vision: Every day, we provide the support, education, and research that will help everyone impacted by Parkinson disease live life to the fullest.

We won't stop until we make Parkinson's no one's disease...and hope you won't stop your most generous support either! The Programs and Services Committee asks that each of you find five people impacted by Parkinson's and tell them about the Greater St. Louis Chapter of the American Parkinson Disease Association. Help us raise awareness not only during the month of April, but all year 'round. And most importantly, remind your physicians of the importance of referring individuals with Parkinson's to the American Parkinson Disease

Association. Please continue to share your enthusiasm about our programs and services as well as the literature, DVDs, newsletters, and educational symposiums that have benefited you, your family and care partners. It is vital to everyone's progress with PD that they have all of the information available to help them on this unique journey. No standard trajectory or path exists but our goal is to help everyone

impacted by this disease anticipate and navigate the clinical, emotional and social aspects of Parkinson's.

In the introduction to the new resource guide *Parkinson's 360°*, the Michael J. Fox Foundation share a poignant passage that I share with you: "People living with PD today have reason for great optimism about their own futures with Parkinson's and that of the entire Parkinson's

community. Research is rapidly moving forward, bringing us closer to a deeper understanding of the disease, concrete ways to diagnose and measure PD, better symptomatic therapies and ultimately a cure. New symptomatic medications are making it through the drug development pipeline to pharmacy shelves. Therapies that could potentially modify the course of the disease are in clinical trials. Parkinson's surgical procedures and devices are improving. Options are continually expanding to support you and your ability to live life with Parkinson's to the fullest at every step of your journey." That is our wish for you- growing old and living well with Parkinson's for many, many years to come.

#### LIVE STREAMING - EXERCISE CLASSES

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non-residents.

**Yoga** – Thursdays at 2:30 p.m. at the APDA Resource Center in Chesterfield, MO. No registration required. All mobility levels welcome.

**Movement Training** – A dynamic standing class on Fridays at 10:00 a.m. at

Friendship Village – Sunset Hills in South County. Call 636.778.3377 to register, as space is limited.

BIG for Life – a class for graduates of the LSVT BIG program. Mondays at 10:00 a.m. at the Blessing Wellness Center in Quincy, IL. Call 217.223.8400 to register (ask for Home Care).

#### Be Well with Parkinson's -

Wednesdays at 10:00 a.m. at the Blessing Wellness Center in Quincy, IL. Call 217.223.8400 to register (ask for Home Care). All mobility levels welcome.

LINK MAY 2017 VOLUME 31, ISSUE 2

## GET TO KNOW THE BOARD- VOLUNTEERS AT YOUR SERVICE



Matt Schumacher - President

Matt has been associated with the organization for over five years. In 2015 and 2016, Matt chaired the APDA Golf Classic in Memory

of Jack Buck, the organization's largest fundraiser to date, helping raise more than \$300,000 for Parkinson's therapies and research. Matt's involvement stems from his mother, who lived with PD for over 20 years and passed in 2016 due to complications associated with the disease. He currently serves as a Principal at Schumacher Creative where he helps clients develop communication strategies for both internal and external audiences.



Rebecca Bruchhauser Farris - Vice President

Rebecca is Director of Donor Relations for State Policy Network (SPN). She serves as a liaison between SPN

and its investors. Her professional history includes more than 15 years of management and sales experience, in addition to strategic planning, business development, marketing, event planning and fundraising experience. Rebecca serves on the Greater St. Louis Chapter of the American Parkinson Disease Association Executive Board to honor her father's 35-year battle with the disease. She enjoys traveling, cooking, floral arranging and gardening.



**Ted Hume - Vice President** 

Ted has had Parkinson's for nine years, and he realized quickly after his diagnosis that his neurologist had provided him with medication for PD but not

much information on the many difficulties that may lie ahead as the disease progressed over time. As an entrepreneur who had started and sold four separate insurance businesses, Ted immersed himself in his options. That's when he learned about how

fortunate we are to have many support groups and services through the APDA of Greater St. Louis Chapter. Ted has been blessed to live a pretty normal life because of his involvement and is proud to support expansion of the Chapter's services to reach as many people with Parkinson's and their families as possible.



Kevin Fairlie – Vice President

Kevin is a healthcare attorney in St. Louis. After serving as General Counsel to a variety of healthcare entities for more than 15

years, Kevin established Fairlie Law, LLC, where he is Managing Member advising healthcare clients around the country. He is a graduate of the University of Missouri -School of Law and the University's graduate school of Healthcare Administration. He is an avid Mizzou sports fan. Kevin and his wife Lauren, live in the Shaw neighborhood of St. Louis with their daughter Emma. Kevin is particularly passionate about causes related to Parkinson disease. PD has had an impact on Kevin and his family over a number of years with both his father and grandmother being diagnosed with the disease.



Brian Hantsbarger – Treasurer, Chair-Budget Committee

Brian is a Principal in the Business Services Department at Conner

Ash. He has over 35 years of experience working in the areas of individual taxation, healthcare practices and professional services companies. Brian's focus includes reviewing individual and business returns and tax consulting. He is also responsible for pension administration and consulting with business owners on a daily basis. Brian has served as Treasurer of the Greater St. Louis Chapter of the American Parkinson Disease Association since 2007. He was a good friend of Jack Buck, who passed away from Parkinson's, and Brian greatly admired

Jack. Brian wants to build and support the services for people with PD in our region, and his tenure on the board has given him that opportunity.



## Dennis Barnes - Director, Chair-Marketing Committee

Dennis Barnes Jr. is the president of Wunderman St.

Louis and Chief Client Officer of Wunderman Health. He was the founder and president of Marketing Direct Inc. (MDI), an integrated marketing services company focused on the healthcare industry. Dennis has more than 20 years in the direct marketing field; he founded MDI in 1997, and it was acquired by Wunderman in December 2010. A graduate of the Massachusetts Institute of Technology Birthing of Giants program for entrepreneurial excellence, Barnes earned one of only 60 program positions from a field of 600 nominees worldwide.

Dennis was previously the president of the St. Louis Chapter of the Young Entrepreneurs Organization and was on the board of directors of the Magic House in St. Louis. Dennis has a relative with Parkinson's and is passionate about raising awareness of Parkinson's in the community.



#### **Christine Eason - Director**

Christine is Associate Director of Communications at Webster University and a proud advocate of her father, Russell Wells, who has defiantly and

tenaciously lived and thrived despite a Parkinson's diagnosis more than a decade ago. She is an experienced integrated marketing communications professional, with extensive experience working within the non-profit and education industries. Prior to joining the board, Christine served on the Epworth Children and Family Services Board of Directors and she is an active volunteer in Parkway School District. She is married and has two children.

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## DID YA KNOW - DID YA KNOW?

PARKINSON's 360° is a new publication and an excellent guide through Parkinson disease. It can be ordered through michaeljfox.org.

A decade of the *LiNK* quarterly newsletters (2007-2017) have been archived on the stlapda.org website. Find valuable resources and useful tips for daily living, strategies for symptom management and advice for care partners in these pages.

There are three newly released publications from the National Parkinson Foundation including: Mood:

A Mind Guide to Parkinson's Disease,
Managing Parkinson's Mid-Stride, and
Psychosis: a Mind Guide to Parkinson
Disease.

These booklets are in addition to the wonderful Rainbow Series of booklets which may also be ordered through the NPF or downloaded from their website.

The U.S. Food and Drug Administration (FDA) recently approved **Xadago** (safinamide) from Newron Pharmaceuticals for people with Parkinson disease who are now taking levodopa but experiencing "off" episodes. "Off" episodes

are times when Parkinson's symptoms, such as tremor or difficulty walking, return despite medication. They are more common as disease progresses. Xadago is indicated as an add-on therapy for those taking levodopa/carbidopa.

This new therapy is a monoamine oxidase (MAO)-B inhibitor, a type of drug that allows dopamine to function for a longer period of time. Other types of MAO-B inhibitors that are FDA approved to treat PD include selegiline

(Eldepryl, Zelapar) and rasagiline (Azilect).

There are even more therapies to address "off" symptoms not far behind. For the sudden and unexpected return of PD symptoms, an inhaled form of levodopa and an under-the-tongue preparation of apomorphine are in the late stages of development. Check with your physician for information on these and other medications utilized for the treatment of PD.

Washington University School of Medicine,
Neurology Department, just received their third
National Institutes of Health (NIH) grant to investigate longitudinal
progression of Parkinson disease, identify biomarkers, and
determine underlying brain pathology.

## FALLS IN PARKINSON DISEASE: CAN THEY BE REDUCED OR PREVENTED?

RYAN DUNCAN, PT, DPT AND BETH CROWNER, PT, DPT, NCS, MPPA, DEPARTMENT OF PHYSICAL THERAPY AT WASHINGTON UNIVERSITY

Falls are common in people with Parkinson disease. Investigators report that more than 60% of people with PD experience more than one fall over the course of the disease. Furthermore, the frequency of falls tends to increase over time. The consequences of falls range in severity from a bump or bruise to broken bones or head injuries. While falls lead to physical injuries, we also know that people with PD who fall lose confidence in their balance and walking abilities. This can lead to immobility and deconditioning. Though reducing one's physical activity inherently reduces the risk for falls, this has its own set of consequences that ultimately may lead to worsening of PD and limit a person's willingness to leave their home and go out into the community.

Up until a year or two ago, evidence for interventions that reduced falls was lacking. The good news is that several recent studies suggest that exercise programs may reduce

**Did You** 

Know?



falls. A study out of Australia, done by Meg Morris and colleagues, noted that 8 weeks resistance training or movement strategy training led to a reduction in falls over the following year. Another study, led by Colleen Canning and colleagues, demonstrated a non-significant reduction in falls in a group of people with PD who took part in balance, walking and strength training 3 times weekly for 6 months. Interestingly, a group with less severe PD fell less following exercise, while a group with more severe PD fell more. The authors suggest the increased falls in those with worse PD could have been due to increased physical activity and balance confidence following the exercise program.

It is possible that these exercise programs reduced falls because they were designed to target specific risk factors for falls: impaired balance, difficulty walking, freezing during walking and reduced lower extremity

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## NON-PHARMACOLOGICAL MEASURES TO TREAT ORTHOSTATIC HYPOTENSION (OH)

HORACIO KAUFMANN, MD, PROFESSOR OF NEUROLOGY, MEDICINE AND PEDIATRICS, DIRECTOR, DYSAUTONOMIA CENTER

of orthostatic ymptoms hypotension (OH) include dizziness/ lightheadedness, feeling fatigue/tiredness, shortness of breath, changes in vision, pain in neck and shoulders or chest pain. Symptoms of OH can be improved with time, patience and non-pharmacologic changes. It is tempting

to try to control OH only with medications. However, these are not usually effective enough and may have adverse effects. Treatment of OH is more successful if nonpharmacologic measurements are implemented as well.

Following is a series of steps to improve symptoms of OH. All steps may be implemented at the same time. If performed properly, these can lead to a dramatic improvement of OH, even with no medications.

1. Liberalize water intake. People with OH need more water than healthy people, and people with OH should be drinking 3 quarts/ day (~2.5 liters). Ideally, it is best to drink water and supplement it with salt (see point #2). Tea coffee increase urine output so they may worsen your symptoms. Sports drinks,

juices and non-diet beverages are not recommended due to their high-sugar content.

- 2. Liberalize salt intake. Add as much salt to your meals as you can handle. Increasing salt in your meals will help increase your blood pressure. Most people do not need to take salt tablets. In fact, salt tablets may cause abdominal discomfort in some individuals.
- 3. Wear compression stockings (also known as TED stockings). These can be found in medical supply stores.

Compression stockings will reduce

the venous pooling that occurs when standing up and, therefore, will increase your blood pressure when standing. There are several strengths for stockings. You can first try a medium strength (i.e., 20-30 mmHg). To be useful, compression stockings should be worn up to the

## THESE ARE HIGH-GLYCEMIC CARBOHYDRATES THAT YOU SHOULD REDUCE/AVOID:

Potatoes	Rice Cakes	Chocolate
Yams	Oatmeal	Full fat milk
Candy	Wheat	Watermelon
Bagels	Grits, Cereal (corn flakes, etc.)	Bananas
White Bread	Soft drinks	Grapes
White Pasta	Bottled juice (orange, apple, etc.)	Rye
Pizza	Cakes	Yogurt
Corn	Cookies	Corn Syrup
Rice	Ice cream	Maple Syrup

## TRY TO INCREASE LOW-GLYCEMIC INDEX **CARBOHYDRATES IN YOUR DIET, INCLUDING:**

Whole-wheat bread	Pears	Lentils
Whole-wheat pasta	Peaches	Soybeans
Brown rice	Just squeezed juice	Cashews
Pearl barley	Prunes	Peanuts
Skim milk	Beans	Carrots
Reduced-fat yogurt	Black-eyed peas	Almonds
Apples	Chickpeas	Nuts
Grapefruits	Peas	Quinoa
Oranges	Hummus	Olives

abdomen. Stockings up to the knee only are not as effective. You do not need to wear the stockings while sleeping.

- 4. Wear an abdominal binder (i.e., a velcro belt around your belly). This can be found in medical supply stores. The mechanism is similar to that of the compression stockings. You do not need to wear it during sleep.
- 5. Sleep with the head of the bed raised at least 30 degrees (ideally 45-50 degrees). This is useful because people with orthostatic hypotension frequently have supine hypertension (high blood

pressure when lying down). To avoid supine hypertension, never lie flat. Sleeping with the head of the bed raised will also reduce urine output, making you wake up less times to urinate at night, and will improve your blood pressure in the morning. The best way to raise the head of the bed is to get an

> electric bed or an electric mattress. These are commercially available in several sizes. Other, less efficacious ways to elevate the head of the bed are by using a wedge or by putting some books/bricks under the upper feet of the bed.

- Drink 500 ml of cold water 30 minutes before getting out of bed in the morning. This will increase your blood pressure when you get up. Drinking 500 ml of water in any other moment of the day will also increase your blood pressure. You may use this on an as needed basis (but make sure you drink, in total, around 3 quarts/day of liquids)
- 7. Start a physical therapy program. In people with OH, physical exercise will decrease blood pressure. But exercise is crucial to keep muscles active. Therefore, in order to avoid low blood pressure when exercising, people with Parkinson's should perform recumbent exercises (e.g., recumbent bicycle,

The best exercise is, by far, performed in a swimming pool. This is because the hydrostatic pressure of the water will prevent falls in blood pressure. While you are in the water, you will feel much better, and you should be able to exercise without significant symptoms. The better your physical shape, the less intense your symptoms of OH will be.

elastic bands, rowing machine, etc.).

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## A DAY IN THE LIFE OF A PARKINSON WARRIOR

A.C. WOOLNOUGH

A.C. Woolnough spent 37 years in public education as a teacher and principal in California, Idaho and Alaska. He is active in the PD community as an advocate, writer and speaker. He just finished participating in his 13th research study. This article originally appeared in **The River Journal**, a North Idaho and Western Montana magazine, and is reprinted with permission.

t's been said that if you've met one person with Parkinson disease (PD), you've met one person with Parkinson's. That's because each person with PD presents differently—despite several common possible symptoms. There are at least five common motor symptoms of PD (including tremors, balance issues, slowness, freezing and dyskinesias [uncontrollable movements]), and well over fifteen non-motor symptoms. The number of possible combinations are immense. No wonder Parkinson's is

called a *snowflake disease*— every instance is unique.

I am fortunate that I have what is called *tremor dominant PD* because my primary motor symptom is shaking. My nonmotor symptoms include apathy, loss of sense of smell (and taste), lack of facial expression, soft voice and having to pee a lot more often. I say that I am *fortunate* to have this type of PD because, statistically, it is the slowest progressing and least likely to lead to dementia.

To provide another contrasting example, I recently interviewed a friend with PD who I'll call Pete. I asked him about his symptoms, what a typical day is like, his concerns and anything

else he'd like to share. What follows are his responses.

After 11 years with PD, Pete deals with several motor symptoms including tremor and loss of fine motor control. He has slight dyskinesia manifested by jaw quiver and occasional arm swipes. Pete's biggest concern is falling. In the past, falls have resulted in face plants and a trip to the hospital with a broken back after tumbling down stairs. Fortunately, his medication seems to be working and there have been no recent falls.

Non-motor symptoms are worse for Pete. Soft speech and constipation (affecting about 75% of people with Parkinson's) are bothersome, but his version of *restless leg syndrome* (where it feels like bugs are crawling under his skin) makes sleep difficult.

Coupled with his *REM sleep disorder* (acting out dreams), fatigue is also an issue. During one episode of sleep disorder, Pete fell out of bed, flailed around and ended up with a broken computer and a few bruises. What doesn't bother him so much, despite the scary-sounding name, is his *Parkinson's psychosis*. This is manifested by hallucinations—seeing things and people that aren't there. Unfortunately, a few years ago, Pete retired due to PD-related cognitive issues. He was easily distracted and found it

hard to focus on a task for very long—important abilities for an engineering consultant.

Part of Pete's daily routine is taking seven different PD drugs (in addition to medications for acid reflux and hypertension) five different times during the day in various combinations. The schedule and timing are critical for these substances to be effective.

Despite these constraints, Pete is concerned with other people and their feelings. He finds that most people pretend not to notice his motor symptoms (perhaps because they are uncomfortable or don't want to offend), and he would prefer it if people simply made a comment or asked a question.

Walking, cycling and kayaking are his favorite outdoor pastimes. Pete's favorite activity, ever since he was little, is *tinkering*. Pete describes this as "finding more complex ways to do simple things." He summarized his overall philosophy: "While having to make accommodations for my symptoms, I will live life to the fullest extent possible."

**Each person with Parkinson's is a warrior**—battling our symptoms and limitations. Despite our willingness to face adversity (do we have a choice?), sometimes we win the day's battle and sometimes not. As my favorite panel (of more than 2,000) in the Parkinson's Quilt states: **Courage doesn't always roar like a lion... sometimes after a hard day, it whispers to try again tomorrow.** 



# FORECASTING SUNSHINE & BLUE SKIES FOR MAY 15 AND ANOTHER BANNER GOLF TOURNAMENT THIS YEAR!

The annual APDA Golf Classic in memory of Jack Buck will take place at Algonquin Golf Club on May 15. All of the golf slots were sold out by the end of March! However, we have tickets remaining for cocktails and dinner. Much gratitude is extended to our generous sponsors, golfers and guests who stepped up to the tee in our 19th year with record-setting support, contributing to what promises to be another banner year with this spring fundraiser.

We are pleased to announce that the St. Louis Cardinals GM, John "Mo" Mozeliak, returns as Honorary Chairperson for the eighth consecutive

year. Mo's grandmother and father-in-law were both diagnosed with Parkinson disease, and we are grateful that Mo remains passionate about his involvement with our organization and this cause. One of the highlights of the evening is the Q and A session with John Mozeliak and KMOX Sports Director and broadcaster, Tom Ackerman. Last year, over \$140,500 was raised to support our expanding programs and services and to fund our \$100,000 grant to the Advanced Center for Parkinson Research at Washington University, one of only eight such centers in the country.

WE WISH TO
RECOGNIZE THE
FOLLOWING
SPONSORS
FOR THEIR
CONTRIBUTIONS
AND GIFTS TO
THIS YEAR'S
TOURNAMENT:

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St. Louis Cardinals

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### NON-PHARMACOLOGICAL MEASURES TO TREAT ORTHOSTATIC HYPOTENSION (OH)

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Therapies such as yoga or Tai Chi are highly advisable too.

- **8.** The following factors worsen OH (i.e., decrease blood pressure) and should be avoided (or can be used right before going to bed to lessen supine hypertension during nighttime):
  - a. Hot and humid temperatures
  - **b.** Physical exercise (see point #7)
  - c. Dehydration (see point #1)
  - d. Alcohol
  - e. High glycemic index carbohydrates. Try to reduce high-

- glycemic carbohydrates in your meals. Also try to have several, small meals (5-6) instead of the three traditional meals.
- 9. Be aware of your symptoms. If you experience symptoms of orthostatic hypotension, you will find relief by performing physical counter-maneuvers (making a fist, crossing your legs, clenching your buttocks) useful to increase your blood pressure when you are standing. If these counter-maneuvers are not enough, please, sit or lie down quickly to avoid fainting and getting injured.

Remember: non-pharmacological measures are the key to the management of orthostatic hypotension.

## **OPTIMISM WALK 2017**

MIKE GARAVALIA, CAMPAIGN MANAGER AND SARAH SCHMERBER, PROGRAM DIRECTOR, GREATER ST. LOUIS CHAPTER -APDA



Our Optimism Walk, Saturday, June 10, is fast approaching! Become part of an extraordinary national grassroots movement to mobilize and inspire everyone to help find a cure for Parkinson's. We would love to have you join us and make this day a special gathering for every person with Parkinson's, their families and care partners.

A great opportunity to help is by forming an Optimism Walk Team. You can form your own team with family and friends, join a team with your exercise class or support group, or walk with our APDA team. Gather your friends, family, neighbors and colleagues to support the fight against PD. To register please go to: stlapda.org/walk/ and follow the prompts on the screen. As a participant, you will play an important role in raising community awareness of Parkinson's and providing the financial support that will make a difference in the lives of those who can and do benefit from APDA programs and services. The entry fee per team member is \$40 for adults and \$15 for children 12 and under. All registrants

will receive a t-shirt and walk finishers will receive a medal.

The event is for all age

groups, from grandparents to grandchildren, and will include family-friendly entertainment, vendor booths, food and demonstrations of the wonderful programs offered by the Greater St. Louis Chapter. Our Optimism Walk is an untimed event allowing everyone the freedom to choose to run or walk a distance that they feel comfortable with that day (anywhere from ¾ of a mile to a full 5K). If you're unable

Lace up your sneakers on June 10 and help make a difference in the fight against Parkinson's!

to walk, you can just come out to enjoy the event with your friends and family.

Our Optimism Walk fundraising goal is \$60,000. We would like each team to attempt to raise a total of \$1,500. Reaching this level of support will give us the ability to maintain our services, fund critical research, raise advocacy efforts and

develop new programs for an ever-growing group of individuals.

Every team achieving the \$1,500 level will be listed on our website and in the *LiNK* newsletter as an outstanding supporter of the fight against Parkinson's. The top fundraising team will be introduced at the walk as the "Walk Champion" and each team member will receive a Certificate of Recognition.

Every nine minutes a person is diagnosed with Parkinson's. With age being the only known risk factor, the number of individuals affected will grow rapidly as our population ages. A successful walk on June 10 will provide the support to fulfill the increasing requests for our programs and services.

Please help us exceed our 2017 Walk fundraising goal!

It starts with our leadership in the community. Because of your commitment, dedication and hard work, we will achieve the ultimate goal of making Parkinson's no one's disease and enabling individuals with PD to live life to the fullest. Thank you for taking the lead in the fight against Parkinson's and inspiring hope.

## FALLS IN PARKINSON DISEASE: CAN THEY BE REDUCED OR PREVENTED?

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strength. In addition to recommending regular exercise, we would like to offer some practical tips that you might use to reduce fall risk.

**Use nightlights.** Your balance is decreased when you are unable to see the environment. If you don't like having a light on throughout the night, nightlights are available that only turn on when they detect movement.

Always wear shoes with backs. Loose fitting footwear like slippers often increases shuffling and doesn't offer the stability that tennis shoes do.

## Remove throw rugs and clutter from your home environment.

These things create hazards that make it difficult to maneuver safely within your home.

Focus on one thing at a time. Some people are less stable when they perform dual tasking (i.e., talking or carrying objects) when they walk. If you find that you are less stable in these circumstances, it would be best to avoid them.

Consider use of an assistive device. A cane or walker can increase your stability during movement. Talk to your physical therapist if this is something you are interested in.

Physical therapists (PT) are experts in designing exercise and fall prevention programs that improve mobility and reduce fall risk. Given that everyone with PD presents differently, it is preferable to see a physical therapist with a strong background in working with PD. Seek a referral from your neurologist or primary care physician for a PT evaluation and subsequent treatment.

LiNK MAY 2017 VOLUME 31, ISSUE 2

## BICYCLE, BICYCLE (I WANT TO RIDE MY BICYCLE)

SCOTT JOHNSON, REPRINTED WITH PERMISSION OF THE NWPF, ORIGINALLY APPEARING IN THE SUMMER 2016 EDITION OF THE PARKINSON'S POST.

doctor telling Tim Fletcher in 2012 that he had Parkinson's disease left him in a rare state of inactivity. Like many people who hear the sobering news, Fletcher was paralyzed by fear. "It's that moment when you're admitted to a club you didn't want to be a part of," he recalled recently. And yet Fletcher couldn't find his way into any kind of membership. Fifty years old and with two teen-aged sons, Fletcher reached out but soon realized that most people with Parkinson's were older and at different stages of their lives. He attended a HOPE Conference® in Seattle and was devastated by the physical signs of suffering and the visible progression of the disease. An avid biker, swimmer, hiker and runner, Fletcher started reading up on Parkinson's and learned that the most important thing to do was to maintain some kind of active lifestyle. He knew he needed to find a group of people with PD who were willing to get each other moving.

Over the next few weeks, months and years, Fletcher began building

up a community of like-bodied adults whose goal was to exercise both their mind and their body. He initially sent out 10 invitations for a bike ride, and all 10 people showed up. Four years later, his group has blossomed to 26 members, and Fletcher is always open to adding more. "It started organically, with me reaching out to a few people, and then it started growing by leaps and bounds," he said. The group

has plenty of physical activity, from bike rides to hikes, but it's mostly about being part of a community. It's not a support group, per say, but Fletcher's network is designed to help people cope with Parkinson's together by staying active and connected.

"For some people, (Parkinson's) makes their lives smaller because it can be very awkward socially," Fletcher explained. "Your hands tremble when you reach for your wallet, your gait is different. You're very conscious of these things, so you become house-bound. Your world shrinks. "It's important when diagnosed with Parkinson's to exercise not only your body but also your mind. Read, take on more hobbies. Do something to challenge your mind, not just your body."

Some of the more popular activities are the ones that stress the social over the physical. Fletcher's group often gathers to play pool and video games. The group can also be found gathering for a barbeque or for a beach outing. Just getting out of the house and spending quality time having fun with other people with Parkinson's is enough to help find some kind of peace. "When you

first get diagnosed, you're overwhelmed with all the information," Fletcher said. "When you're able to talk to one person, they're either managing the symptoms or they're not, but you feel like they're fighting the fight with you."

Several members have branched out into smaller friendships of two or three, and that's the kind of social expansion Fletcher hoped to see. Fletcher has benefitted from the group both socially and physically. He's nearly as active as he was before learning he had Parkinson's, often going on four-hour mountain-bike rides. "I find that when you do things that take immediacy and adrenaline, it takes a lot of focus and attention," Fletcher said. "I feel like I don't have Parkinson's at all, like the symptoms almost disappear during that time." The daily activity has been a huge part of Fletcher's ability to cope with his Parkinson's. "Some people approach Parkinson's like: 'Learn to accept it. The disease is there, so accept it," he said. "I see it more like a combatant, an opponent that I wake up to every

day. Sometimes I conquer it, sometimes I don't. It's like going to battle, going to war, every morning. You've got to be aggressive. You can't be like: 'This is my lot in life.'"

The daily battle isn't always easy. "If someone who doesn't have Parkinson's doesn't work out for a few days, they might feel a little sluggish or less alert," Fletcher said. "If I don't work out every single day, I feel

like my body's stuck in cement. That's my motivation. The mornings are the hardest, when you feel it the most, so it's a challenge. But that's what gets me going." Staying active, and depending on others, has been the best way for Fletcher to take his Parkinson's journey. Seeking help from those who walk in similar shoes is the first step. "Parkinson's hits men more than women, and men are less likely to reach out, for whatever reason," Fletcher said. "My generation is not always into talking or reaching out. The tone of the group isn't a support group, like, 'How have you been doing?' It's, 'Let's do some active, fun things.' Even pool or ping-pong is great. Something to get you moving. "Mostly, it helps me feel really good and connected. It makes people feel like they're a part of something. That's what I like about it. You've got to have something good come out of this, right?"

Anyone interested in organizing an outing for active people with Parkinson's can email Tricia Creel at tcreel@stlapda.org or call 636.778.3377.



## TRIBUTES & DONATIONS 01/01/2017-03/31/2017

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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Sid & Fran Axelbaum

#### Jamie & Adam Heldman on their wedding

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#### George Marble on his special 75th birthday

Karl & Debbie Guyer

#### John Mozeliak on his birthday

Debbie Guyer

#### Steve Rosenblum on his special birthday

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#### Abby & Lily Schreiber on their 6th birthday

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#### **Jack Strosnider on his** birthday

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## Dr. Joel Perlmutter

## Shirley J. Waide

**Catherine Ray** 

#### Jack Strosnider

Mike Scheller

#### Arnold Goldman

#### Mike Stern on the honor of Agro Man of the Year.

Larry & Gail Glenn

#### Mary Strauss for the wonderful gift of "Finding Neverland"

Robert & Jackie Sanderson

#### Jean M. Strieder

Henry Strieder

#### Jack Strosnider for a speedy recovery

Karl & Debbie Guyer

## **Sharon Wells**

St. Peter's Evangelical Church

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01/01/2017-03/31/2017

continued from previous page

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## GET TO KNOW THE BOARD- VOLUNTEERS AT YOUR SERVICE

continued from page 5



## Rob Goren - Director, Chair-Programs & Services Committee

Rob Goren is President and CEO of Delta Dental of Missouri and its subsidiaries. At the helm in this role since

2015, Rob is responsible for all aspects of the organization's operations, culture and successes. He sets overall strategy and direction for short- and long-term business initiatives and drives growth and revenue to fulfill the organization's ongoing social mission to improve oral health.

Rob's mom was diagnosed with Parkinson's about ten years ago. When he moved to St. Louis in 2009, Rob wanted to find a way to get involved in the healthcare community and help out with a cause that he could be passionate about. Rob reports that he has "learned so much about Parkinson's, which has allowed me to not only help my mom, but also hopefully positively impact the lives of the numerous folks in the St. Louis region that are fighting this disease."



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#### Joe Marchbein - Director

Joe is a CPA with Rice
Sullivan, LLC where his
experience includes
tax planning, research
and review, and IRS
examinations and
procedures. He specializes

in handling issues involving tax controversy. His past work experience includes various managerial positions with the Internal Revenue Service and in public accounting. Joe has served on the board almost since its inception, joining in the 1990s, and served as President of the Board for almost a decade.

Joe is an adjunct in the Master of Accountancy and former adjunct in the Master of Science Taxation Program at Fontbonne University, where he was awarded Outstanding Faculty Member in 2004.



#### **Caryn Mefford - Director**

Caryn is a Senior Account Manager at FindLaw-A Thomson Reuters Business. Optimism, mindfulness, and leadership are key tenets to her approach to

life. Caryn has over 20 years of non-profit board experience and a career marked by innovating solutions which focus on keeping the customer experience at the forefront of all strategic innovation. Caryn's innate curiosity and desire to help others craft solutions informs her developing side business as a Life Coach. Caryn joined the board to lend enthusiasm and energy to assist the organization's mission. These are values she learned early in life from her father who has Parkinson disease. Caryn also enjoys exercise, travel and spending as much time as possible with her family.



#### **Kathy Schroeder - Director**

Kathy is a Principal in the Entrepreneurial Services Group at Brown Smith Wallace with over 30 years of experience in public accounting with specific

emphasis in tax planning, compliance and research for individuals and businesses. She also spends much of her time consulting with small business clients on operating, financial and tax matters. Kathy got involved with the APDA after her husband, Doug, was diagnosed with PD. Both Kathy and Doug have spent much time volunteering for and supporting the APDA's various programs for many years.

## **OPTIMISM EVENTS**

The Iron Aces, a motorcycle club, held a Rodeo & BBQ Pig Roast for close to 100 people. They raised \$1,000 which was donated to the Greater St. Louis Chapter of the APDA in honor of a member and his father who both have PD. The Iron Aces choose a different charity each year, and we were delighted to be the recipients of such generosity this year.

The Cassville School District Girls Basketball fundraiser in loving memory of coach Chris Shore's father, Charles Shore, raised close to \$300 this year for the Greater St. Louis Chapter of the APDA. They alternate years for conducting this fundraiser for our Chapter which serves the bi-state region.

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## 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 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	4th Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2678
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	11:00 AM	Tricia Creel, DPT	678.951.3361
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. TBD	3rd Tuesday	6:30 PM	Joe Vernon	314.614.2182
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. TBD	3rd Tuesday	6:30 PM	Doug Schroeder	314.985.7708
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	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



## 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	314.471.6302
Webster Groves	St. Louis	Laclede Groves 723 S. Laclede Station Rd.	3rd Wednesday	3:00 PM	Shawn Riley, MSW	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.	3rd Thursday	2:00 PM	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
Carlinville	Macoupin	Carlinville Area Hospital Medical Office Building-Community Room 20613 N. Broad St.	3rd Wednesday - Schedule can fluctuate, please contact leader to verify date and time.	10:00 AM	Amy Murphy PT, DPT, NCS	217.854.3839
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	Mary DeLong Paula Beals	618.692.1346
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
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	3rd Sunday Odd num- bered 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

LINK MAY 2017 VOLUME 31, ISSUE 2





## Missouri and Illinois Exercise Classes

Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our funding comes from donations, so we encourage those who attend multiple classes to make a \$5 per week donation. This helps us defray the cost which run around \$10 per person. 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. No RSVPs are required. Check our website, <a href="https://www.stlapda.org">www.stlapda.org</a>, or call 636.778.3377 to find out any changes since publication.

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Clayton	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Chesterfield	St. Luke's Deslodge Outpatient Center, 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Ann Towey, PTA	314.205.6934
Chesterfield	Friendship Village 15201 Olive Blvd. Friendship Hall-Door #5	Tuesday	1:30 PM	Travis Harper	314.223.9575
Chesterfield	Circuit/Interval Training 1415 Elbridge Payne, Ste 163	Monday Tuesday	2:30 PM 10:00 AM	Tricia Creel, PT	636.778.3377
Chesterfield	General Chair Side Exercise 1415 Elbridge Payne, Ste. 163	Monday	1:30-2:15 PM	Tricia Creel, PT	636.778.3377
Chesterfield	Tai Chi Parkinson Exercise Suite 1415 Elbridge Payne, Ste 163	Wednesday Thursday Friday	Intermediate- 10:00 AM Advanced- 12:00 PM Beginning- 11:30 AM	Craig Miller	636.778.3377
Chesterfield	Yoga Parkinson Exercise Suite, 1415 Elbridge Payne, Ste 163	Thursday	2:30 PM	Diane Davis	636.778.3377
Florissant	Garden Villas North, 4505 Parker Rd.	Thursday	10:00 AM	Nancy Robb	314.869.5296
Joplin	Mercy Hospital, 100 Mercy Way Conference Room	Monday	2:15 PM	Nancy Dunaway, PT	417.781.2727
Kirkwood	SSM Day Institute 1001 S Kirkwood Rd.	Thursday	1:00 PM	Teresa Godfrey, PT	314.821.7554
Richmond Heights	Parkinson's Performance THE HEIGHTS, 8001 Dale Ave.	Saturday	1:00 PM	Barry Nicholson, Personal Trainer	314.645.1476 (registrations)
Richmond Heights	Tango Convergence Dance and Body Center, 7700 Clayton Rd., Ste 120	Thursday (starts April 20)	10:00 AM	Roxanne Maier	636.778.3377 (registrations)
Ladue	Tremble Clefs Salem United Methodist, 1200 S. Lindbergh Blvd., Lower Level Choir Room	Saturday	1:30 PM	Linda McNair, MT-BC	636.778.3377 (registrations)
South St. Louis County	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
South St. Louis Country	Movement Training Dynamic Standing Friendship Village Sunset Hills, 12563 Village Circle Drive	Friday (starts April 20)	10:00 AM	Beth Templin, PT	636.778.3377
St. Peters	Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle	Tuesday	Dynamic Standing 10:00 AM Chair Exercise 11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Thursdays Spring Session April 3 - June 9	1:45 PM	Alicia Bunn, CTRS	636.896.0999 x21 (Kathleen)
Town and Country	Tremble Clefs Singing West County Maryville University, 650 Maryville University Dr. Walker Building-Community Room	Thursday	1:30 PM	Megan Moran, MT	636.778.3377 (registrations)

	CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
	Carlinville, IL	Movement Training: Dynamic Standing Carlinville Area Hospital, MOB, Community Room 201613 N. Broad	Thursday	10:00 AM	Amy Murphy, PT	217.854.3141 x377
1	Jacksonville, IL	Spirit of Faith Church 105 East Dunlap Street	Wednesday	1:00 PM	Eve Fischberg, OT	217.494.4961
	Quincy, IL	Be Well with Parkinsons Blessing Wellness Center, 4917 Oak Stree	Wednesday	10:00 AM	Rita Arment, PT	217.223.8400 (ask for Home Care) registrations
	Quincy, IL	BIG For Life Blessing Wellness Center, 4917 Oak Stree	Monday	10:00 AM	Rita Arment, PT	217.223.8400 (ask for Home Care) registrations
	Springfield, IL	The Joy of Movement Laurel United Methodist Church, 631 South Grand Ave. West	Tuesday	1:30 PM	Eve Fischberg, OT	217.494.4961

MAY 2017 **LiNK** 

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 adpdastlouis@adpaparkinson.org to let us know! Thank you in advance for helping us spend our resources wisely!

# 2003 AMERICAN PARKINSON DISEASE ASSOCIATION

**GREATER ST. LOUIS CHAPTER** 

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## **SAVE THE DATES**

## **MAY 15, 2017**

Annual Golf Classic in Memory of Jack Buck, benefiting the Greater St. Louis Chapter of the APDA at Algonquin Golf Club.

## **JUNE 10, 2017**

Optimism Walk at Maryville University. Premier year for this signature program. Demonstrations and registration begin at 10:00 a.m. Walk will begin at 11:15 a.m. Food and more displays and performances will continue until 1:00 p.m. Come and bring a team. Proceeds to benefit the Greater St. Louis Chapter of the APDA.

## **OCTOBER 27, 2017**

Mini-Midwest Parkinson
Congress. Held at United
Hebrew Congregation.
Reservations required. Must
select track: Exercise, Care
Partner Concerns, Advances
in Treatment (DBS, Duopa,
Psychosis) 10:00 a.m. –
3:00 p.m. (lunch provided).

## F.O.G. - FREEZING OF GAIT

TRICIA CREEL, PT, DPT, NCS, WELLNESS PROGRAM COORDINATOR, GREATER ST. LOUIS CHAPTER - APDA

Freezing of gait is a symptom experienced by some people with Parkinson disease. Freezing is a temporary, involuntary inability to move. Freezing can occur any time, but most frequently occurs during turns. People who experience

freezing describe it as the feeling that their feet are stuck to the floor. Not all people with PD experience freezing episodes, but those who do are at a much higher risk of falling. There are strategies for overcoming a freezing episode, such as rocking in place or listening to an auditory cue. However, these strategies

cue. However, these strategies are often not effective when the person with PD is rushed or distracted. Medications are also only partially effective in reducing episodes.

Freezing of gait is the result of a complex interplay between motor, cognitive and environmental factors. Recently, research by Fay Horak and Laurie King showed that six weeks of a cognitively challenging

agility boot camp resulted in a

freezing of gait severity
for participants. In
partnership with the
Washington University
Program in Physical
Therapy, the APDA
- Greater St. Louis
chapter is very excited
to announce that we will

offer a Freezing of Gait Boot

Camp starting in mid-June. The

Boot Camp will run for 6-8 weeks. For more information or to pre-register for the Boot Camp, please contact Tricia Creel at 636.778.3377 or tcreel@stlapda.org.