

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

Serving Missouri and Southern Illinois

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AMERICAN PARKINSON DISEASE ASSOCIATION

GREATER ST. LOUIS CHAPTER Strength in optimism. Hope in progress.

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OUR MISSION

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

WHEN THE LIGHTS GO ON

MIKE GARAVALIA, CAMPAIGN MANAGER AND TRICIA CREEL, WELLNESS COORDINATOR, APDA-GREATER ST. LOUIS CHAPTER

It is 7:15 a.m., the door opens and the bell jingles in the darkness announcing the start to another day. Deborah Guyer, Executive Director, hits the switch to the office lights and the Parkinson Resource Center springs to life. The Center is ready to assist people touched by Parkinson's through a wealth of programs and services, most at no cost to the participants.

Soon the phone begins to ring from those seeking support with a wide range of questions. The exercise suite is filled with music keeping the kickboxing class in tempo, and our live-streaming service is providing online access for participants exercising at home. Later in the day, one enthusiastic group will take part in a cognitive stimulation session while another group meets for care-partner support. This is not a special day; it's every day in the Parkinson Resource Center.

The foundation of success in support of the bi-state Parkinson's community is our staff. The APDA-Greater St. Louis team is knowledgeable, compassionate, caring, insightful and professionally trained. They support a large number of programs and services that extend throughout the bi-state region. That includes new and exciting programs like the exercise classes being piloted in four different YMCAs across the region and a care partner "take-a-break" respite day in Illinois.

You are able to visit our website for information, attend a PD 101 session with your family, take part in a freezing of gait boot camp, dance in a tango class, receive the *LiNK* newsletter and visit with our staff

because of generous donors who believe in what we do. We could not do what we are able to do without this generous, unfailing support.

When we ask you to build a team for the Optimism Walk, sponsor a hole at the APDA Golf Classic, or support our year-end appeal, it is because your participation provides for so much. Our mission of every day providing the support, education and research that will help everyone impacted by Parkinson disease live life to the fullest comes with real world expenses. Your limitless generosity is critical.

Our fundraising events and requests for support allow us to:

- Provide innovative programs and services for all impacted by PD, their families and care partners.
- Support professional staff and a worldclass Resource Center.
- Increase the public's awareness of Parkinson's as a major health issue.
- Continually improve our diverse portfolio of educational materials and programs.
- Increase funding of research to find a cure and address symptoms.
- Prepare and plan to meet the growing needs of the PD community.

Thank you for your support of this critical work. The APDA-Greater St. Louis staff is excited to partner with you to continue to set the standard for resources and research for Parkinson disease.

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UNDERSTANDING PARKINSON DISEASE PSYCHOSIS

MEDICALLY REVIEWED BY KAREN ELTA ANDERSON, MD, NEUROPSYCHIATRIST, MEDSTAR GEORGETOWN UNIVERSITY HOSPITAL, WASHINGTON, DC AND ORIGINALLY POSTED AT HEALTHYWOMEN.ORG

Imagine learning to care for a loved one with Parkinson disease (PD),

which is a neurodegenerative brain disorder that affects nearly one million people in the United States. He may move slowly or is rigid, lose his balance easily or shake uncontrollably while resting, which are common symptoms of PD.

But then other symptoms begin to occur. He starts asking why the kids are in the car, but your kids have grown up and moved away. Or he thinks someone is watching him. And, of course, no one is there. Hallucinations and delusions like these are symptoms of Parkinson disease psychosis, which occurs in about 50 percent of people with PD at some point during their illness.

Sometimes described as "tricks" played by the brain, hallucinations can cause a person to see, hear, feel, smell or even taste something that isn't real. A person with hallucinations may say they see people or animals that aren't there. As their hallucinations become more frequent, they may not be able to tell what's real and what's imagined and may react to things that aren't real.

Delusions occur less frequently than hallucinations and are generally more difficult to treat. Delusions are fixed, false beliefs not supported by evidence and often have paranoid themes. A common delusion that occurs in people with Parkinson's is that their partner is having an affair, even if they have been married for decades and their spouse is with them nearly all of the time.

When a loved one is experiencing hallucinations and delusions, it can add more frustration to the already challenging physical limitations of Parkinson's. Research has found that hallucinations and delusions can lead to increased distress, greater responsibility for caregivers, and even nursing home placement.

Yet, as difficult and distressing as these hallucinations and delusions may be, only about 10 to 20 percent of patients who have hallucinations or delusions associated with PD proactively report the symptoms to their health care providers.

That may be because they don't understand that these symptoms are associated with PD or are embarrassed to report that they are experiencing visions and false beliefs. Sometimes these "invisible" symptoms can cause more problems than the motor issues—especially if people with Parkinson's don't seek help. Hallucinations and delusions usually appear later in the disease's progression and often catch caregivers by surprise if they and the doctor are focused on motor symptoms, which are easier to identify.

CAUSES OF PARKINSON DISEASE PSYCHOSIS

The cause of hallucinations and delusions associated with Parkinson's is not clearly understood. The drugs commonly used to treat PD, which raise dopamine levels to improve motor control, can cause physical and chemical changes in the brain that may lead to hallucinations and delusions. In addition, the natural progression of Parkinson disease may cause brain changes that trigger symptoms.

TREATMENT FOR PARKINSON DISEASE PSYCHOSIS

A health care provider can help to identify hallucinations and delusions associated with Parkinson's, monitor signs that symptoms may be progressing and offer ways to help manage any related challenges.

The first step is for the physician to confirm that the hallucinations and delusions are caused by Parkinson disease by eliminating other possible causes. Once the diagnosis is made,

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the health care provider will decide how to treat the symptoms. Treatment may involve adjusting or switching PD medications. Antipsychotic medications also may be used, including an FDA-approved treatment option specifically for hallucinations and delusions associated with Parkinson disease that may be appropriate for some people.

For more information about Parkinson disease and its nonmotor symptoms, such as hallucinations and delusions, visit www.apdaparkinson.org/greaterstlouis.

THE POWER OF MUSIC

MARINA CLEMENTS, SPT. MEDICAL UNIVERSITY OF SOUTH CAROLINA, DPT CLASS OF 2018

There is much to be said about the connection between music and the brain. A song can bring back good memories, a melody can make you tear up and a beat can make you tap your toes. It's no secret that music moves us, physically and emotionally, but just how powerful can it be?

Research in both music therapy and neuroscience has provided mounting evidence that music can affect function in profound ways. Music-based interventions are emerging as a promising rehabilitation strategy to address movement, cognitive and psychological symptoms in all phases of Parkinson disease (PD).

"I think music in itself is healing. It's an explosive expression of humanity. It's something we are all touched by. No matter what culture we're from." – Billy Joel

Music can also make you smarter. Listening to or playing music is an exercise for your brain because multiple areas of the brain are being used simultaneously. Studies have shown that listening, clapping or stomping along to music can improve one's memory and ability to recall words and name items. Playing music also improves selective attention and increases communication between both sides of your brain. In addition, it improves your language skills.

Music can produce substantial effects on movement-related symptoms, and researchers have good reason to believe that it has to do with rhythm. The brain regions that control movement are closely related to the ones that perceive rhythm. In people with PD, this area of the brain changes and may contribute to the inability to maintain a steady gait rhythm—leading to reduced speed, cadence, stride length and step symmetry. Music activates many areas of the brain, and steady rhythms provide an external stimulus that can serve as a template to move better. Research has shown that music-based interventions such as singing while walking, rhythmic auditory stimulation, syncing your gait to your favorite music and participating in music therapy sessions can improve walking speed and cadence, decrease bradykinesia, improve balance and reduce freezing!

Literature also shows that playing and listening to music may modulate emotions, behaviors and even sleep. Music has been clinically proven to reduce stress, reduce depression, elevate mood and decrease anxiety. It has been shown that music stimulates the production of two "feel-good" neurotransmitters--dopamine and serotonin—that are reduced in people with Parkinson disease. Studies have demonstrated that people participating in classes based around music report feeling improved social support, emotional function and quality of life.

There has also been substantial research on the application of music through singing, vocal exercises, Argentine Tango and other styles of dancing. There are many ways to integrate more music into your life.

For ways to incorporate the power of music into your life, consider joining one of the Greater St. Louis Chapter's Tremble Clef choirs or Tango classes. The Joy of Movement dance class in the Springfield, Illinois, also focuses on music and movement.

MAY 2018 **LiNK**

TREMBLE CLEFS

LINDA MCNAIR, MT-BC, CHOIR DIRECTOR, TREMBLE CLEFS OF GREATER ST. LOUIS



Singing in a choir can provide a fun, joyful social outlet, but it can also offer many therapeutic benefits for people with PD. Participating in our Tremble Clef choirs is one way to reap the benefits of shared music-making, and we are pleased to announce that Richard Winter, President of Garden View Care Centers and community

philanthropist, has provided a very generous grant to sponsor two Tremble Clef choirs for the next 12 months. Keeping the arts alive is one of Mr. Winter's passions.

Practicing good breathing techniques so that a louder voice can be achieved and sustained, in addition to practicing use of a wide range of pitch, addresses some of the common voice symptoms present in people with Parkinson's. Approximately 90% of people with Parkinson's experience voice problems, including inadequate volume (soft voice), insufficient breath support (running out of breath while speaking), reduced pitch range (monotonous voice) and poor articulation (slurring).

Because people with Parkinson's may also experience slowness of movement (bradykinesia), engagement in activities becomes more challenging and sometimes results in social isolation. Tremble Clefs provides a strong social support system – yet another benefit! The presence of music and rhythm improves movement, making the choirs even more delightful to attend.

The Greater St. Louis Chapter, through generous grants and donors, sponsors two Tremble Clefs singing groups. They are directed by board-certified music therapists and are specifically designed to meet the goals of improving voice quality and social interaction. The mission of Tremble Clefs is: a) to address vocal concerns that develop as a result of PD, b) to improve posture, balance, and mobility through movement to music, c) to provide an enjoyable and supportive social outlet, and d) to promote Parkinson's awareness through singing.

Weekly group singing also has the additional benefit of improving mood and feelings of camaraderie. No singing or music experience is required! Members rehearse weekly and occasionally perform in the community.

Join us for a Tremble Clef choir performance on Sunday, June 3, at 2:00 p.m. at Salem United Methodist Church in Ladue. You'll go away singing a happy tune and feeling pleased to have experienced the joy of music.

THE ROLE OF NUTRITION IN MANAGING PARKINSON DISEASE

In honor of National Nutrition Month, the Brian Grant Foundation spoke with Parkinson disease nutrition specialist Kathrynne Holden to learn why diet plays such an important role in managing Parkinson disease. Holden is a retired registered dietician, nutrition consultant and author of several research papers and other published works on Parkinson's and nutrition, including the book Cook Well, Stay Well with Parkinson's Disease. The interview which appears below is reprinted with permission from Katrina Kahl, Executive Director, the Brian Grant Foundation, and Kathrynne Holden.

WHY DO YOU BELIEVE NUTRITION PLAYS SUCH A POWERFUL ROLE IN MANAGING PARKINSON DISEASE?

Our bodies constantly build, maintain and repair the cells of our organs, neurons, tissues, blood, muscles and bones. The materials our body needs for this work – protein, essential fatty acids, carbohydrates, minerals, vitamins, antioxidants and fibers – come from the foods we eat. Many of the symptoms of Parkinson disease, such as nausea, appetite loss, depression, loss of smell and taste, difficulty swallowing and unplanned weight loss, lead to nutrient deficiency or outright malnutrition. These cause new complications of their own.

WHAT TYPES OF VITAMINS OR NUTRIENTS DO YOU RECOMMEND PEOPLE WITH PARKINSON'S INCORPORATE INTO THEIR DIET?

Vitamin D deficiency is so widespread among people with Parkinson disease that I recommend everyone have a baseline blood test to see whether they may need supplements – or in extreme cases, even injections of Vitamin D. Deficiency of Vitamin D is associated with weakened bones, falls, fractures and dementia. One Parkinson's study found that persons with higher levels of Vitamin D had less depression, better cognition and lower symptom severity.

The B vitamins-thiamine, riboflavin, niacin, B6, B12, and folatehave been studied and found to be important in preventing

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concerns such as dementia, insomnia, depression, behavior change and neuron degeneration. **Please note that Vitamin B6 can interfere with levodopa.** Calcium, magnesium and potassium (also known as electrolytes) are necessary for normal functioning of the muscles. Without these electrolytes, a condition called "tetany" can occur, causing painful muscle spasms in various parts of the body, including the throat. Calcium and magnesium are also needed for bone strength, which helps prevent fractures as Parkinson's progresses.

YOU'VE CONSULTED WITH THE MEDICAL COMMUNITY ABOUT THE BENEFITS OF FOODS RICH IN OMEGA-3 FATTY ACIDS FOR PARKINSON'S. COULD YOU EXPAND ON THAT?

The omega-3 fatty acids-eicosapentaenoic acid (EPA), docosahexaenoic acid (DHA) and alpha linolenic acid (ALA)-are called essential fats because the human body can't make them; they must come from our food. These fats form a large part of the gray matter of the brain, and deficiency is associated with depression, cognitive impairment and dementia. A small study of men with both Parkinson disease and major depression found that fish oil supplements reduced depression scores. Fatty fish contains EPA and DHA; some plant oils contain ALA, which our body can convert (to a limited degree) to EPA and DHA.

YOU'VE ALSO PLACED A LOT OF EMPHASIS ON FIBER-RICH FOODS FOR THOSE LIVING WITH PARKINSON'S. WHY IS THAT?

Fibers play important roles in Parkinson disease, first, because insoluble fiber helps manage constipation, which is very common. In fact, constipation is often among the earliest signs, occurring even before diagnosis. Fiber can help prevent constipation and its more serious complication, bowel impaction. A second role for fiber is that many different kinds of fiber are needed as food by the friendly bacteria in our intestines, known as microbiome. The importance of microbiome cannot be overstated, as it affects immune response, mental health, intestinal health and blood glucose control.

WHAT ARE THE MUST-HAVES THAT SHOULD BE ON ANYONE WITH PARKINSON'S SHOPPING LIST?

I recommend they try to eat at least two or three varieties of the following foods weekly:

- Beans, either dried or canned, are great sources of thiamine, folate, magnesium, potassium and fiber.
- Nuts and seeds, whether sunflower, sesame, flax and pumpkin seeds, peanuts, almonds, walnuts and Brazil nuts, offer thiamine, riboflavin, B6, magnesium, alpha linolenic acid.
- Whole grains like oats, whole wheat, buckwheat, millet, barley, quinoa, rye, brown rice and popcorn will provide thiamine, fiber, and complex carbohydrates.
- A variety of vegetables and fruits, including dark leafy greens, mushrooms, broccoli, potatoes and sweet potatoes, avocados, bananas, apples, citrus fruits, grapes, and kiwi fruit, contains riboflavin, niacin, B6, folate, calcium, magnesium, potassium and a variety of fibers. Be sure to consume a few different ones each week.
- Fatty fish such as salmon, sardines, tuna (fresh, frozen or canned) and halibut; eggs; chicken or turkey white meat; occasional beef or pork contain niacin, B6 and B12. Fatty fish and eggs also have omega-3 fatty acids and Vitamin D.
- I suggest yogurt for calcium, Vitamin D (if fortified), riboflavin, B12 and probiotic bacteria.
- I recommend onions, apples, bananas, whole grains, dried beans, flax seeds, raw honey, cocoa powder and dark chocolate for their prebiotic, soluble and insoluble fibers.

WOULD YOU MIND SHARING YOUR PERSONAL CONNECTION TO PARKINSON DISEASE AND WHAT INSPIRED YOU TO SERVE THIS COMMUNITY?

My interest has always been in nutrition for older adults, and this led me to Parkinson disease. I quickly discovered that, while Parkinson's throws out many obstacles to nutritional health, there was little to no dietary information specific to Parkinson's and little awareness that PD could cause slowed stomach emptying, dysphagia and difficulty chewing. People were suffering from malnutrition because they had a hard time managing eating utensils. I've since made it my goal to research, study, write and provide guidance for both health professionals and the public. And I continue to learn from all the wonderful people with Parkinson disease and their super care partners who give me so much more than I can return.

TRIBUTES & DONATIONS 01.01.2018 TO 03.31.2018

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. Please note that only donations of \$25 or greater are listed.

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Jeff Rose Audrey Ruester Donna & Donald Sartor DeWane Schneider Judith Schuster Bill Sorrell Mel & Sharon Spiegelglass

Carol & Rod Stecher Patricia Swope James Twellman

Rose & Rick Walters David Wiese Delphine Williams Jan & Joseph Zeller Vivian Zvibleman

\$100-\$499

Robert Babione Bill Billings Don Brohm Linda Bouchard Chris & Ralph Burgess Jerry & Cecile Davis Robert Green Carolyn Haeger Halo Investments Dorothy & Dave Heaton Kathleen Holas Erica & David Hood Arlene & Seymour Katz Linda & Steve Kilgore Cheryl & Martin Kinert Nancy & Mike Klein Mary & Bill Kottkamp Deanna & Russell Lentz Freda Lohr Linda Mahan Jeanne & Philip McDermott Linda & Lewis Miles Lonn Pressnall Mary & William Seman Rev. Eugene Selzer Cynthia Smalley Opal & James Turnbough

\$500-\$1,999

Mary & Phil Estep Al Forsman Gary Hicks Jim Janson, Piasa Charitable Foundation

\$25,000+

James and Alison Bates Foundation

ANNUAL CAMPAIGN Up to \$99

John Jaeger Edith Kapfensteiner

\$100-\$499

Charlotte Eldredge Joann & Brian Elliott Sandy & Richard Ellison Richard Kohn Ann & Larry Mauch Diane Novak Susan & John Rothenheber

\$500-\$1,999

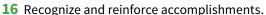
Fox Family Foundation Al Forsman

GUIDELINES FOR ADULT CHILDREN: MAKING DECISIONS AND MAINTAINING INDEPENDENCE

JAMES A. MURPHY, LCSW, CHICAGO, IL

- 1 Understand that older adults are people first and old second, meaning that they have the same wants and needs as people of all ages.
- 2 Understand the basic anchorages in life: an intact body and the image of such, an acceptable home, financial security and a meaningful purpose in life.
- 3 Be alert to the distinction between quantity-of-life and quality-of-life. (Some people prefer to have a shorter life span and in exchange have a better quality-of-life).
- 4 Understand risk taking: Older adults have the right to take risks as long as other people are not hurt.
- **5** Always consider the psychological significance of decisions.
- 6 Know the difference between being overly protective versus allowing people to participate in the joys and sorrows of life.
- 7 Be aware of who is responsible for another person's happiness. While it is our responsibility to offer options, these options may be rejected.
- 8 Recognize the difference between being helpful versus being controlling.

- **9** Be aware of the distinction between happiness and pleasure. While a person with a chronic illness may not be happy, the person still has the ability to experience pleasure.
- **10** Understand the distinction between benign memory loss, memory loss due to treatable and reversible conditions and memory loss due to dementia.
- **11** Whenever possible, involve the older adult in the process of pulling together facts about their current life situation and in decision-making. Include family members as much as reasonably possible.
- **12** In moments of crisis and decision-making, realize that it is natural to defend against internal or external threats. The older adult may not process what is being discussed, and non-hostile, warm, accepting repetition is needed. With firm yet compassionate communication, the chance of real understanding is increased but not guaranteed.
- **13** Avoid unproductive arguments.
- **14** Encourage older adults to do as much as possible for themselves.
- **15** Be aware that older adults should not allow anyone of any age to control them. In a non-hostile fashion, older adults may





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WHO IS FIT BEHIND THE WHEEL?

PEGGY BARCO, OTD, OTR/L, SCDCM, CDRS, WASHINGTON UNIVERSITY MEDICAL SCHOOL - PROGRAM IN OCCUPATIONAL THERAPY

It is now well known that Parkinson disease (PD) is not strictly a disease of the elderly – it can impact young and middle-aged adults as well. For all age groups, driving is one of those important functional activities that allows independence and the ability to stay connected in the community. Driving, while very important to one's independence, is also a public-safety issue – especially when a medical condition exists. Being aware of the changes that can occur with various medical conditions, how these changes can impact driving safety, and using good judgment regarding one's own driving ability are important in determining who is fit behind the wheel.

PD is commonly known as a disease that affects movement and motor function. It is widely recognized that in addition to the motor symptoms of PD, there can also be vision, cognitive and perceptual changes – especially as the disease progresses. The non-motor symptoms that are most common in PD include reduction in contrast sensitivity in vision, difficulties in proprioception and difficulties with cognitive functioning. All of these non-motor areas have the potential to greatly decrease driving safety.

- 1 Decreased contrast sensitivity: Limited contrast sensitivity affects the ability of an individual with PD to detect visual stimuli in low contrast environments such as pedestrians in crosswalks on a dark or foggy day. Results of a recent study confirmed that drivers in low contrast conditions with PD displayed less control over their vehicles, had slower responses to hazards and committed more safety errors than those without PD.
- **2 Decreased proprioception:** Proprioception refers to the sense of knowing where one's body is in space and can decline as part of normal aging, as well as with PD. While evidence on the impact on driving is lacking in this specific area, difficulty positioning the foot correctly on the gas or brake pedal could be a hazard.
- 3 Difficulties with cognitive functioning: Evidence is showing that cognitive changes can occur as PD progresses these changes can include decreased attention, memory, problem solving, planning, visuospatial abilities, and decision making (e.g., executive function). Reports from driving studies indicate that individuals with PD (especially those with cognitive changes) have been found to be less safe drivers resulting in more driving errors during driving studies. While many persons with PD (especially those in the early stages) remain safe drivers, it is very important to be aware of the possible changes that can occur as the disease

progresses. Being aware of changes in cognitive abilities is a positive indicator in remaining a safe driver. For example, if an individual is aware of the cognitive changes, he or she might be more likely to adapt their driving accordingly, such as restricting themselves to daytime driving only, driving only in familiar areas and/or only in less congested times of the day.

HOW DO YOU KNOW IF YOU NEED A COMPREHENSIVE DRIVING EVALUATION?

Often families and individuals have difficulty assessing driving safety objectively. Indications of driving difficulties can include, but are not limited to, a recent history of accidents/tickets, difficulties maintaining good lane positioning, delayed responses to traffic lights or planning for what lane to get into, difficulty deciding when it is safe to make a turn, relying on non-drivers in the car to help with decision making and getting lost while driving. If you, your family member, or physician are concerned about your driving safety, it is advisable to seek a comprehensive driving evaluation. Some individuals also choose to have "baseline" evaluations from year to year to determine if any of their driving abilities have changed.

WHAT IS A COMPREHENSIVE DRIVING EVALUATION?

A Comprehensive Driving Evaluation (CDE) is usually provided by an occupational the rapist who has a specialty certification in Driving Rehabilitation. A CDE usually takes a few hours and includes clinical testing of visual skills, motor/sensory skills and cognitive functioning related to driving. In addition, the CDE includes an onroad assessment that looks at how the individual actually drives in real traffic conditions. For safety, the on-road assessments are done in a driving evaluation car with a passenger side brake. Once both the clinical and on-road driving assessment are completed, the driving rehabilitation specialist can provide recommendations to the individual, family and physician regarding driving safety.

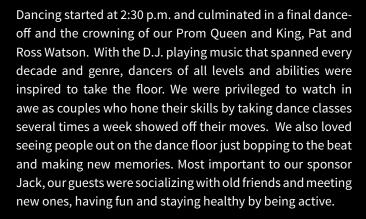
For further information regarding driving assessments and research studies regarding driving abilities that you might be eligible to participate in through Washington University School of Medicine, please call: 314.658.3846 DRIVING Connections in partnership with The Rehabilitation Institute or Peggy Barco, OTD, OTR/L, SCDCM, CDRS, at Washington University School of Medicine- Program in Occupational Therapy.

Pankinson Prom





Our dancing shoes were tapping as we twirled, boogied and shimmied at the Parkinson Prom on Sunday, April 15! The beautifully renovated Congregation Shaare Emeth was the stage for over 130 people with Parkinson disease, family, friends and volunteers who danced all afternoon to the sounds of D.J. Terre LeGrande. The dance was once again sponsored by our wonderful South County Support Group Co-Facilitator, Jack Strosnider. We had a belated celebration for Jack's 93rd birthday with a cake featuring his signature line, "Good For One Hug."



Special thanks to Lynda Wiens for the beautiful centerpieces, Jack for sponsoring this outstanding event, and to our volunteers including graduate students from Washington University and Maryville University Physical and Occupational Therapy Programs for helping with this friend-raiser. We hope to see more of you register for future dances. This prom was certainly the social event of the year!







Photos by Zach Dalin Photography



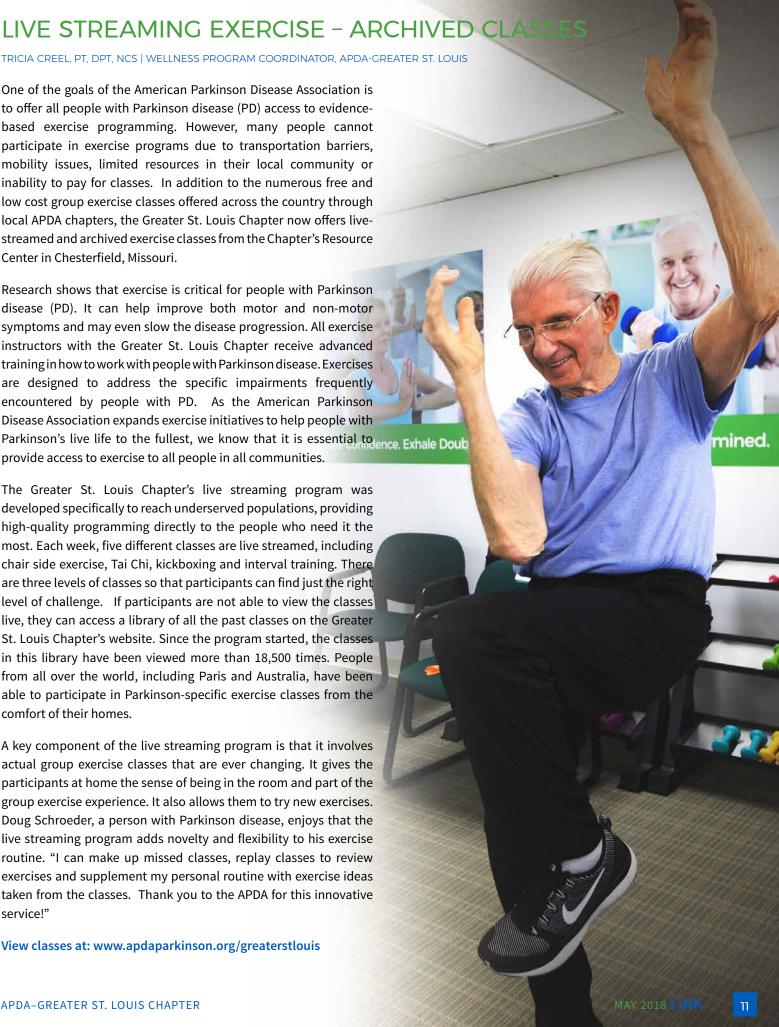
One of the goals of the American Parkinson Disease Association is to offer all people with Parkinson disease (PD) access to evidencebased exercise programming. However, many people cannot participate in exercise programs due to transportation barriers, mobility issues, limited resources in their local community or inability to pay for classes. In addition to the numerous free and low cost group exercise classes offered across the country through local APDA chapters, the Greater St. Louis Chapter now offers livestreamed and archived exercise classes from the Chapter's Resource Center in Chesterfield, Missouri.

Research shows that exercise is critical for people with Parkinson disease (PD). It can help improve both motor and non-motor symptoms and may even slow the disease progression. All exercise instructors with the Greater St. Louis Chapter receive advanced training in how to work with people with Parkinson disease. Exercises are designed to address the specific impairments frequently encountered by people with PD. As the American Parkinson Disease Association expands exercise initiatives to help people with Parkinson's live life to the fullest, we know that it is essential to ence Exhale Doub provide access to exercise to all people in all communities.

The Greater St. Louis Chapter's live streaming program was developed specifically to reach underserved populations, providing high-quality programming directly to the people who need it the most. Each week, five different classes are live streamed, including chair side exercise, Tai Chi, kickboxing and interval training. There are three levels of classes so that participants can find just the right level of challenge. If participants are not able to view the classes live, they can access a library of all the past classes on the Greater St. Louis Chapter's website. Since the program started, the classes in this library have been viewed more than 18,500 times. People from all over the world, including Paris and Australia, have been able to participate in Parkinson-specific exercise classes from the comfort of their homes.

A key component of the live streaming program is that it involves actual group exercise classes that are ever changing. It gives the participants at home the sense of being in the room and part of the group exercise experience. It also allows them to try new exercises. Doug Schroeder, a person with Parkinson disease, enjoys that the live streaming program adds novelty and flexibility to his exercise routine. "I can make up missed classes, replay classes to review exercises and supplement my personal routine with exercise ideas taken from the classes. Thank you to the APDA for this innovative service!"

View classes at: www.apdaparkinson.org/greaterstlouis





HOPE IN MOTION - OPTIMISM WALK

Saturday, June 2, 2018

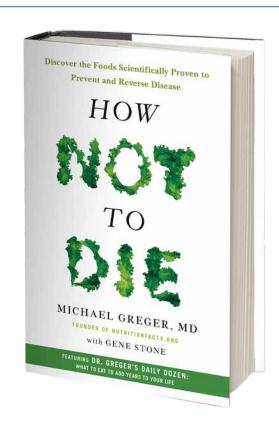
Maryville University 650 Maryville University Drive Town & Country, MO 63141

Check-in: 9:30am - Walk: 10:00am Register online today! apdaparkinson.org/greaterstlouischapter

You don't want to miss the **2nd annual APDA Optimism Walk on Saturday, June 2.** This is a wonderful opportunity to be part of a nationwide movement to mobilize and inspire people to help put an end to Parkinson disease. Proceeds from the event will help us provide programs, services and research in alignment with our mission of every day providing the support, education and research that will help everyone impacted by Parkinson disease live life to the fullest.

You will recall that at our inaugural event in 2017 we raised over \$105,000 and had 550 participants. Our goal for 2018 is to raise \$125,000 with 750 participants. The Optimism Walk is a family-friendly event with activities for people with Parkinson disease, their families, friends and neighbors. We will assemble in the quadrangle at Maryville University at 9:30 a.m. to kick off the event with team photos, face painting, balloon twisting, visits to sponsor and vendor booths, and warm-up exercises. Then walkers will begin the short walk around the campus at 10:00 a.m., and afterwards, we will cool off with a tasty treat at the ice cream social.

Sign up today on our website www.apdaparkinson.org/greaterstlouis or call 636.778.3377. If you are unable to join us in person, create a virtual team by asking friends, family and neighbors to join your fundraising efforts. Lace up your sneakers and step up to help us put an end to Parkinson disease.



Save the Date -October 4 - for the first Elliot and Mary Ann Stein Speakers Series, featuring Michael Greger, MD, FACLM, a physician, New York Times bestselling author and internationally recognized speaker on nutrition, food safety and public health issues. Stay tuned for more details! HOW NOT TO DIE: The Role of Diet in Preventing, Arresting, and Reversing Our Top 15 Killers.

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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.apdaparkinson.org/greaterstlouis, 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, PT	636.778.3377
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
Creve Coeur	St. Louis	Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl. CLI Rm. 415	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. 415	3rd Tuesday	6:30 PM	Doug Schroeder	314.985.7708
Desoto	Jefferson County	StoneBridge - The Villas 1550 Villas Drive	Last Wednesday	3:00 PM	Jennie Lessor	636.586.6559
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
Hermann	Gasconade	StoneBridge- Frene Valley 1800 Wein St. Activity Room	4th Wednesday	5:00 PM	Emilie Hegerfeld	573.486.3155
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	First Presbyterian Church 100 E. Adams Ave. Room 009 LL	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
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
St. Louis (city)	St. Louis	Health & Wellness Center-Paraquad 5200 Berthold Ave.	1st Tuesday	11:00 AM	Melissa Smith, OTR/L	314.289.4202
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider Amanda Landsbaum, MS	314.846.5919 636.778.3377
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	6:00 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



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.apdaparkinson.org/greaterstlouis, 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	Dustin Heiser	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 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	Lin Smith Mary DeLong	618.344.0680 217.204.2137
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut–Meeting Room 2	1st Wednesday April-December	6:00 PM	Larry and Karen Ladd	217.377.4973
Charleston	Coles	LifeSpan Center 11021 E. Co. Rd. 800N	Last Tuesday	1:30 PM	Jean Shode	217.639.5150
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 contact leader to verify date and time	10:30 AM	Terri and Dave May	217.224.7027
Quincy For Caregivers Only	Adams	Quincy Public Library 526 Jersey St.	2nd Thursday 4th Tuesday contact leader to verify date and time	12:30 PM	Terri and Dave May	217.224.7027

Non-affiliated support groups are listed on our website only.

- Washington University

University Movement Disorders

There are new exciting PD clinical trials underway at **WASHINGTON UNIVERSITY MOVEMENT DISORDERS** clinic. For more information about these research opportunities, please contact Stacy Pratt at **314.362.3372** or **stacyapratt@wustl.edu**

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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 unless noted. Check our website, www.apdaparkinson.org/greaterstlouis, or call 636.778.3377 to find out any changes since publication. Online videos of classes are available at all times on our website.

CITY	MEETING SITE	LEVEL	DAY OF MEETING	TIME	LEADER(S)	PHONE
Clayton	Fit 'n Fun The Center of Clayton,50 Gay Ave., Mind/Body Room	Level 1	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Chesterfield	Movement Training St. Luke's Outpatient Center, 111 St. Luke's Center Drive Bldg. B, Suite 14B	Level 1	Monday	10:00 AM	Ann Towey, PTA	314.205.6934
Chesterfield	Circuit/Interval Training 1415 Elbridge Payne, Ste. 163	Level 2-3	Monday Tuesday Thursday	2:30 PM 10:00 AM 1:00 PM	Tricia Creel, PT	636.778.3377
Chesterfield	Movement Training 1415 Elbridge Payne, Ste. 163	Level 1	Monday	1:30-2:15 PM	Tricia Creel, PT	636.778.3377
Chesterfield	Tai Chi 1415 Elbridge Payne, Ste. 163	Level 2 Level 1	Wednesday Friday	10:00 AM 11:30 AM	Craig Miller	636.778.3377
Chesterfield	CycleBar, 1657 Clarkson Rd.	Level 2-3	Tuesday	1:00 PM	Alana Krone	636.778.3880 (registration)
Chesterfield	Exercise for Parkinson's (cycle + strength) Chesterfield YMCA , 16464 Burkhardt Place	Level 2	Friday	12:30 PM	Angela Weaver	636.532.3100 (registration)
Creve Coeur	Box Your B.E.S.T. The J's Staenberg Family Complex, 2 Millstone Campus Dr.	Level 3	Tuesday Thursday	1:00 PM	Joe Ryan	314.442.3452 (registration)
Florissant	Movement Training Garden Villas North, 4505 Parker Rd.	Level 1	Thursday	10:00 AM	Nancy Robb	314.869.5296
Kirkwood	Movement Training Bethesda Hawthorne Place, 1111 S. Berry Rd.	Level 2	Thursday	1:45 PM	Teresa Godfrey, PT	314.821.7554 (registration)
Hermann	Movement Training Stonebridge-Frene Valley, 1800 Wein St., Activity Room	Level 1-2	2nd & 4th Tuesday	4:00 PM	Emilie Hegerfeld	573.486.3155
O'Fallon	Movement Training Park Place at WingHaven, Independent Living Fitness Room, 2002 Boardwalk Place Dr	Level 1	Wednesday	10:00 AM	Melissa Handlan, PT	636.778.3377
Richmond Heights	Parkinson's Performance THE HEIGHTS, 8001 Dale Ave.	Level 3	Saturday	1:00 PM	Barry Nicholson	314.645.1476 (registration)
Richmond Heights	Tango Convergence Dance and Body Center, 7700 Clayton Rd., Ste. 120	Level 2	Thursday	11:00 AM	Roxanne Maier	636.778.3377 (registration)
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 (registration)
South St. Louis County	Fit 'n Fun Garden Villas South, 13457 Tesson Ferry Rd.	Level 1	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
South St. Louis County	Movement Training Friendship Village Sunset Hills, 12563 Village Circle Drive	Level 2	Friday	10:00 AM	Beth Templin, PT	636.778.3377
Ste. Genevieve	Movement Training Community Center, 21390 Hwy 32	Level 2	Thursday	11:00 AM	Ketta Hill, PT	573.883.5244
St. Louis City	Paraquad Health & Wellness Center, 5200 Berthold Ave.	Level 2-3	Thursday	10:00 AM	Melissa Smith, OTR/L	314.289.4253
St. Peters	Movement Training Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle	Level 2 Level 1	Tuesday	10:00 AM 11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	Aquatics St. Charles YMCA, 3900 Shady Springs Ln.	Level 1-2	Thursday April 2-June 8	1:45 PM	Alicia Bunn, CTRS	636.896.0999 x21 (Kathleen)
Town and Country	Tremble Clefs Maryville University, 650 Maryville University Dr. Walker Building-Community Room		Thursday	1:30 PM	Megan Moran, MT	636.778.3377 (registration)
Washington	Exercise for Parkinson's (cycle + strength) Four Rivers YMCA , 400 Grand Avenue	Level 1	Tuesday Thursday	1:00 PM	Tim Peters	636.239.5704 (registration)

CITY	MEETING SITE	LEVEL	DAY OF MEETING	TIME	LEADER(S)	PHONE
Belleville	Exercise for Parkinson's Cycle & Strength East Belleville YMCA, 2627 Carlyle Avenue	Level 1	Monday Wednesday	12:00 PM	Stefanie McLaughlin	618.236.9983 (registration)
Carlinville	Movement Training Carlinville Area Hospital, Medical Office Building, Community Room, 20613 N. Broad	Level 2	Thursday	10:00 AM	Amy Murphy, PT	217.854.3141 x377
O' Fallon,	Exercise for Parkinson's Cycle & Strength O'Fallon YMCA, 284 North Seven Hills Road	Level 1	Tuesday Thursday	12:00 PM	Amy Weisbrodt	618.628.7701 (registration)
Springfield	Joy of Movement (Dance) Laurel United Methodist Church, 631 South Grand Ave. West	All Levels	Tuesday	1:30 PM	Eve Fischberg, OT	217.494.4961

Non-affiliated exercise classes are listed on our website only.

APDA-GREATER ST. LOUIS CHAPTER

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

PLEASE NOTE OUR NEW EMAIL ADDRESSES AND WEBSITE



INFORMATION

apdastlouis@apdaparkinson.org **WEBSITE**:

www.apdaparkinson.org/ greaterstlouis

EMAIL:

Debbie Guyer, Executive Director dguyer@apdaparkinson.org

Sarah Schmerber, Program Director sschmerber@apdaparkinson.org

Tricia Creel, Wellness Coordinator tcreel@apdaparkinson.org

Amanda Landsbaum, Wellness Coordinator

alandsbaum@apdaparkinson.org

Meredith Wallus, Office Coordinator mwallus@apdaparkinson.org

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 moder. It is the label of the moder of the label of the moder of the label of the moder of the formation of the sole of the formation of the label of the moder.

2003 AMERICAN PARKINSON DISEASE ASSOCIATION

GREATER ST. LOUIS CHAPTER

Strength in optimism. Hope in progress.

1415 Elbridge Payne Road, Suite 150 Chesterfield, Missouri 63017

Address Service Requested

JOIN US FOR
THE FOLLOWING
PROGRAMMING AND
EVENTS IN 2018!

MAY 21

20th Annual Golf Classic in Memory of Jack Buck

Algonquin Golf Club, RSVP required

JUNE 2

2nd Annual Optimism Walk

in Memory of Walter & Connie Donius, Maryville University

OCTOBER 4

Elliot & Mary Ann Stein
Speakers Series - Dr. Michael

Greger, How Not to Die, RSVP required

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