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 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.

Filled With Gratitude— Hard To Say Goodbye

Deborah Dalin Guyer, Executive Director, APDA – Greater St. Louis



As I sit and ruminate on the path that my career has taken since I left the field of Speech Pathology, I am experiencing both sadness and joy—sad to not have delivered on the promise of a cure for Parkinson disease (PD), but joyful to see all the progress made over my tenure with the introduction of new medications and knowledge of the importance of aerobic exercise in slowing down the progression of the disease.

I can think of no other way I would rather have spent the final decades of my career than in this role.

With overwhelming gratitude for the opportunity to serve this community, initially on the Board of Directors, as Information & Referral Coordinator, and then Executive Director (ED) of the Greater St. Louis Chapter, I am writing my final *LiNK* newsletter. The decision to retire from a job that has been so much more than a “job” was difficult, but the time is right for the American Parkinson Disease Association (APDA) to transition to a new ED and for me to spend more time with my family, who have always been 110% supportive and patient in my efforts to serve our Parkinson’s community.

Serving with the APDA since 1997 has enriched my life in so very many ways and it has truly been a privilege. My hope is that you will continue to live life to the fullest in the face of the challenges you experience and to feel the credible hope that Peter Dunlap-Shohl wrote about in our August *LiNK*.

Continued on next page >

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> *Continued from front cover*

One of my colleagues, Susan Reese, former Coordinator of the APDA Young Onset Information and Referral Center, wrote this in her Coordinator's column years ago, and I want to share it with you here:

Life is full of plans that we make for ourselves. We plan trips, we plan the number of children we want to have, we plan for our future. We wish, we hope, we dream, and we plan. What we do not plan for is the uninvited intrusion into our lives of Parkinson disease. When the doctor utters that diagnosis to us, all those hopes and dreams and plans flash before our eyes and are often displaced by uncertainty and concerns. In the blink of an eye our status changes: we become "patient" or "caregiver." Oftentimes we emerge from the doctor's office with little more than the diagnosis. We need education and reassurance. We need answers to our questions. And in time, we may need to speak to others who also walk in our shoes.

Our staff offers reassurance, individual PD101 sessions, resources, programs, newsletters, support groups, and educational materials to help individuals with Parkinson disease, care partners, and service providers navigate the issues of day-to-day living with PD. The Greater St. Louis Chapter exists to support everyone in your family and will help meet the challenges that PD presents to ALL individuals affected by this disease. We are here for you. In putting together our annual plan in August, we identified a need for additional focus on care partners, who for the longest time have not garnered the attention they deserve. Susan continued:

Those who live with and care for the person with PD need special support of their own. Understandably, the focus of attention is often on the person with Parkinson's, and the needs of the care partner may be overlooked. Care partners may forego attending to their own needs because of the demands on their time and energy that comes from increased family responsibilities and supporting the person with PD. It is important to remember that the care partner needs "maintenance and repair." Just like a car, a care partner will "break down" if regular maintenance and "filling the tank" are not attended to.

In the coming weeks, I will have opportunities to speak with you and to help with a smooth transition before my departure in January. I have cherished the ability to meet and work with all of you throughout my tenure with APDA. I will miss you but will never be farther away than a phone call or an email. In the words of Winnie the Pooh, "How lucky I am to have something that makes saying goodbye so hard to do." 🍯

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.



Dear Friends,

As President of the APDA – Greater St. Louis Chapter Board of Directors, I am honored and privileged to be a part of the amazing work that is taking place right here in our community. Through the dedication of our staff and volunteers, we have made a huge impact on people with Parkinson’s and their families through the support, education, and research the association provides every day. The ADPA – Greater St. Louis Chapter allows those touched by Parkinson disease to live life to the fullest.

As we approach the fall, we reflect on our past accomplishments and future goals. In 2019, we:

- » **Hosted the 2nd Annual Elliot & Mary Ann Stein Speaker Series** to raise awareness about good health and the APDA – Greater St. Louis Chapter. Dr. Wendy Suzuki, an internationally-recognized speaker and author of the book, *Healthy Brain, Happy Life*, spoke to 400 guests to demonstrate the power of the brain and body connection, particularly to help those impacted by Parkinson disease, Alzheimer’s, and dementia.
- » **Served over 1,100 people with Parkinson disease** through exercise classes, informational programs, and support groups across the bi-state region.
- » **Presented the 2nd Annual Midwest Parkinson Congress**, featuring presentations from industry leading professionals on topics ranging from the latest research to adaptive equipment to estate planning. We had over 800 people in attendance representing ten states.
- » **Held the 21st Annual APDA Golf Classic in Memory of Jack Buck**. With a beautiful day of golf and a sold-out dinner, our generous donors raised more than \$210,000 to help support programs and services for people living with Parkinson disease.
- » **Added several new programs including the first-of-its-kind Driving Retirement Workshop** which covers how Parkinson’s can affect driving, signs of unsafe driving, options to assess safety with driving, local transportation options, and how to create a personalized retirement plan; and expanded our partnership with many YMCA locations throughout the bi-state region to make programs more accessible to you where you live.
- » **Funded \$125,000 in our annual grant to the APDA Advanced Research Center for Parkinson Disease at Washington University** for continued research in the treatment and prevention of Parkinson’s.
- » **Distributed more than 600 Welcome Packets** providing printed educational information to individuals diagnosed with Parkinson disease.
- » **Conducted more than 100 individual PD101 sessions with newly diagnosed individuals and family members** where Parkinson disease is explained in an easy to understand way, available resources are shared, and any personal questions or concerns are addressed.

Without your support and dedication, these impactful events, research, and programs would not occur. We appreciate everything you have done to help make all of these achievements possible, but we cannot stop now. As we approach 2020, we will offer even more programming, events, and funding for research, and drive even greater awareness of the resources available to those in need in our community, and we look forward to your continued partnership to help us provide these resources.

Best wishes for a happy holiday season and healthy new year,

Christine Alsop

President, Board of Directors, APDA – Greater St. Louis Chapter

APDA Advanced Research Center for Parkinson Disease at Washington University in St. Louis



Joel S. Perlmutter, MD,
Department of Neurology,
Head of Movement Disorders
Section, Washington
University School of Medicine

Substantial progress has been made this past year at the APDA Advanced Research Center for Parkinson Disease (PD) at Washington University.

We welcomed a new movement disorders faculty person, Dr. Isabel Afradique-Dunham, officially in July. Dr. Afradique-Dunham completed her neurology residency at Universidade Federal Fluminense in Brazil and another neurology residency at Baylor. She then finished a movement disorders fellowship with Dr. Joe Jankovic at Baylor. She is an outstanding clinician and we are delighted to have her join our faculty. Below is a summary of some of the work made possible by support received from the APDA – Greater St. Louis Chapter.

One major area of research continues to be the identification and validation of measurements that we call biomarkers of PD progression, with a particular focus on cognitive difficulties that may develop. We continue to use MRI scans to measure functional networks that relate to various types of brain activity needed for movement and attention. Dr. Meghan Campbell, in collaboration with Drs. Jackson, Koller, Snyder, Kotzbauer, and me, just had a new paper accepted to the journal, *Neurology*, that demonstrates longitudinal changes in MRI-measured brain networks, along with measures of proteins in the spinal fluid, that may function as new markers of disease progression. Dr. Jay Maiti led a team with Drs. Koller, Snyder, Tanenbaum, Norris, Campbell, and me

that discovered strong relationships between selected behavioral skills resultant from MRI resting state brain network functional connections that link the back part of the brain (cerebellum) and higher brain areas. The value of these types of studies is that they provide potential targets for new treatments. Collection of this data also permitted Dr. Maiti to obtain a mentored career award sponsored by the National Institutes of Health (NIH).

We also continue to develop new brain measurements using PET scans. We published several papers on refining new methods to measure cholinergic neurons – neurons that use acetylcholine as a neurotransmitter. These new PET radiotracers have been developed with radiochemistry colleagues including Drs. Yue, Luo, Jin, Kaneshiga, Parsons, Tu, and me. We have now done PET using these new radiotracers in more than 75 participants in our long term study of people with PD. Dr. John O'Donnell, supported through grants from the APDA, continues to analyze these PET data and is comparing these measures with those from brain tissues acquired from those who donated their brains after death to our research (ongoing studies by Drs. Kotzbauer and Perrin). Dr. O'Donnell continues to be supported by a fellowship grant from the NIH that he was able to obtain again with preliminary data acquired by support from the APDA – Greater St. Louis Chapter.

Another major event is a new grant in collaboration with Dr. Robert Mach at the University of Pennsylvania. This grant reflects a collaboration among the University of Pennsylvania, Washington University,

Yale, University of Pittsburgh, and University of California at San Francisco. The purpose of this large project is to develop new PET radiotracers—including one to measure alpha-synuclein, which is the abnormal protein deposited in the brain in people with PD. This is a huge effort and also involves Drs. Tu and Kotzbauer at Washington University. This five-year study started in September, 2019, and again much of the preliminary data was collected with the help of the APDA – Greater St. Louis Chapter.

In addition to becoming an outstanding movement disorders clinician, our fellow, Dr. John Younce, has been working on several research studies. One demonstrates the safety and efficacy of Deep Brain Stimulation (DBS) for people greater than 75 years old with PD. He also has been working on completing a manuscript describing how preoperative MRI scans of the brain can be used to predict outcomes after DBS surgery. This study combined post-operative PET measures of DBS-induced blood flow responses in the brain with resting-state networks measured with pre-operative MRI scans. The post-op DBS blood flow scans helped us identify what parts of the brain we should explore for key resting state networks found in the MRI scans collected before surgery. These regions may then help us analyze preoperative MRI scans in the future to help predict DBS outcomes. These studies take advantage of methods that we developed last year to precisely identify the location of DBS electrodes in the brain, which was more precise than had been possible in the past.

Finally, the St. Louis community, and now the NIH, have helped us

continue our work to develop the drug carboxyfullerene, sometimes called synoxyzime, which has the potential to slow the progression of PD. As you may recall, Dr. Laura Dugan developed this drug when she was at Washington University, and together she and I demonstrated in animal models that this had potential for reversing damage to the nigrostriatal pathway, one of the key brain pathways that degenerates in people with PD. In the last couple of years, we have been trying to develop a means to measure brain inflammation and reactive oxygen species, sometimes called free radicals, since we believe that carboxyfullerene works by reducing these destructive processes in the brain. Although initially no methods existed to measure reactive oxygen species in the brains of humans while alive, and the current methods to measure neuroinflammation remained unsatisfactory, we have now made dramatic progress with the support of the APDA – Greater St. Louis Chapter and others. We were able to obtain sufficient preliminary data from three new PET radiotracers for these measures so the NIH awarded us another five-year grant. The new grant started this past summer, and we are

We continue to make substantial progress thanks to the support of both donors and volunteers. Both of these components permit us to move forward.

pushing forward but we still need help. We want to move faster than the NIH support permits. Through the support of generous individual donors, we have now accelerated this research. In fact, we are about to purchase a new PET scanner that will be used for this project. Your gifts of support to the APDA – Greater St. Louis Chapter have helped move this exciting research forward. We are putting together a manuscript describing the initial findings – which are quite surprising. Once this manuscript has been accepted for publication, we will be able to share results that address our new measures of neuroinflammation. We are also moving forward on a parallel track to prepare for a phase 1 clinical trial in humans. This drug has never been given to humans, so the phase 1 trial will be to determine safety and tolerability. We are cautiously optimistic about this line of research. We have three important goals: first

to measure neuroinflammation and reactive oxygen species in the brain – important for testing carboxyfullerene in human trials. These measures will also be extremely valuable for testing other potential treatments. Second, we want to determine how well these measures reflect target engagement by carboxyfullerene. As noted, this will help us personalize testing this drug for people with PD. Third, we want to determine if carboxyfullerene can slow PD progression in people. That will take more time, but we are definitely moving in the right direction. Your continued support helps and enables us to move this work at an accelerated pace. These studies have been conducted in collaboration with Drs. Dugan, Norris, Tu, Zhou, Liu, and me.

In summary, we continue to make substantial progress and have been fortunate to obtain new grants to continue our work. Without the support from the APDA – Greater St. Louis Chapter, the progress achieved would not have been possible. Support has included not only your financial support but volunteers willing to participate in our studies. Both of these components permit us to move forward. Thank you for all of your help. 🙌

RESEARCH STUDY AT
WASHINGTON UNIVERSITY
IN ST. LOUIS

Walking Health is Paramount in Parkinson Disease (WHIP-PD)

Program in Physical Therapy
4444 Forest Park Avenue
St. Louis

Boston University –
Charles River Campus
Institutional Review Board
Approved 05/14/19–05/13/20



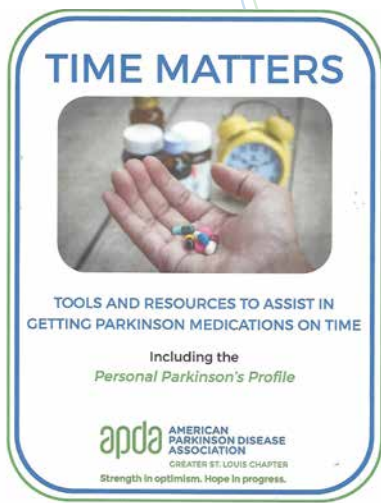
You are invited to participate in a research study designed to improve and support your walking health. The program is intended to be flexible and completed over a 12-month period.

Eligible participants will be randomly assigned to one of two groups. Both groups will have up to 8 visits with a licensed physical therapist. The program will include walking and exercises to improve walking capacity. One group will use an application or “app” through a smartphone or tablet for the walking and home exercise program, and the other group will use photos and paper instructions for the walking and home exercise program.

You may be eligible to participate in this study if you:

- » Have been diagnosed with Parkinson disease.
- » Are able to walk without assistance for at least 10 continuous minutes.
- » Are able to come to the study site at Washington University School of Medicine for physical therapy sessions and evaluation sessions.

For more information call Martha at 314.286.1478



TIME MATTERS!

The APDA – Greater St. Louis Chapter has received consistent feedback that people with Parkinson disease (PD) often do not receive their medications on time when hospitalized or staying in a nursing care facility.

Healthcare staff may not be aware of the following:

- » The complexity of Parkinson's symptoms, including non-motor symptoms.
- » The importance of not missing a single dose.
- » The time-sensitive nature of PD medications.
- » The possible negative drug interactions when taking PD medications.

Missing doses or being late with PD medications can cause significant negative symptoms, including the inability to move well and complete self-care tasks. This can be quite frustrating for the person with PD, the family, and the healthcare providers, and may be misinterpreted as the individual purposefully behaving in an obstinate manner.

People with Parkinson's are hospitalized 50% more than their peers without Parkinson's, and they suffer avoidable complications at a higher rate than non-PD individuals. This frequently results in longer hospital stays and can result in serious complications. We join Parkinson Canada and the U.K. in their campaigns to improve the quality of life of people with Parkinson disease by helping hospital and care facility staff understand Parkinson's better. We want them to understand what happens to people when they don't get their medication on time, as we feel that getting medication on time will shorten hospital stays, reduce the need for readmission after discharge, and ultimately reduce the burden on individuals, families, hospital, and care facility staff.

Consequently, the APDA – Greater St. Louis Chapter formed a Parkinson's Medication Advocacy Committee with the goal of helping people with Parkinson's, their care partners, and family members avoid or resolve any concerns with getting correct medications on time, every time. As a result of these efforts, a new resource has been developed to help prepare for planned and/or unplanned admissions to hospitals and other healthcare settings. *Time Matters*, a 3-ring binder and accompanying short orientation/training seminar, may now be obtained during scheduled training sessions. This binder

includes a number of tools to help individuals, care partners, and healthcare workers:

- » The *Personal Parkinson's Profile* (PPP) keeps essential medical information about the individual with PD in an organized and easily-accessible format.
- » *Planning Ahead* helps prepare for planned and unplanned admissions.
- » *Medication Information* covers common Parkinson medications and medications to avoid or give with caution.
- » *Additional Resources* includes information that may be relevant for hospital stays and/or living in a long-term care facility.

People with Parkinson disease need to get their medication on time, every time, whether at home, in an emergency room, in a hospital, or in a nursing care facility. This could very well mean giving individuals medication at a different time from a facility's usual rounds. Medication-related errors are common in the treatment of individuals with PD when at home, hospitalized, or residing in a nursing care facility. These errors frequently include the timing of medication. Late or missed doses can reduce medication efficacy contributing to motor and non-motor fluctuations and impairing function and quality of life.

In addition to the *Time Matters* binder, the Advocacy Committee is developing information about PD and the medications used to treat it, which will be provided to professionals. This information will cover medications never to be given (or only given with caution) to people with PD, the importance of medications being given on time, and the behavioral changes that occur when medications are not received on time. Even in the best hospitals and emergency rooms, there can be a lack of understanding of PD and a lack of awareness about the critical importance of Parkinson's medication timing. Care facility staff may be unaware that common medications for pain, nausea, depression, and psychosis are unsafe for people with PD. Using the *Time Matters* binder, individuals and their families can work to bridge this gap.

The more information the care facility has, the better equipped they will be to cope with the day-to-day needs of people with Parkinson's. PD medications should be given on the individual's schedule, and not the facility's schedule. We want to promote that medicine should be provided on time, every time, and encourage readers to call the APDA Resource Center to attend a session on medication management and to obtain a *Time Matters* binder. YOU are the best advocate for your own care! 🌱



Amy Counihan, DPT, Medical
University of South Carolina

TANGO!

Tango is an enjoyable way to get moving and reduce the motor symptoms that come with a Parkinson's diagnosis. There have been many research studies completed on this subject, and they conclude that tango is a very effective Parkinson's prescription with zero negative side effects! In a study involving individuals taking weekly tango classes, significant improvements were found in balance, walking cadence, walking speed, fatigue level, and disease severity. These improvements were maintained even 10-12 weeks after ending the tango lessons. Another recent study found that weekly tango classes resulted in significantly improved stability in standing likely due to improvement in the postural strategies employed to maintain balance.

When you dance, your attention is focused on your movements and you learn to move with intention and purpose. When you are dancing with a partner, you can practice movements such as backward stepping, forward and backward turning, and movement initiation in a safe environment, allowing you to improve your technique. Tango is a preferred form of dance for people with Parkinson's as it addresses many of the commonly experienced mobility impairments and is a partnered dance. Dr. Madeleine Hackney, a health research scientist at the Atlanta VA Medical

Center and former professional dancer, focuses on tango rather than other forms of dance in her Parkinson's research because "Tango is multimodal involving spatial awareness, motor control, balance, memory, and coordination to the music with a partner." Tango involves variation of rhythm, unlike other dance forms such as the waltz or foxtrot. Thus when dancing in sync to tango music, spontaneous steps and movements occur to follow the variation in rhythm.

Not only does tango improve mobility, but it leads to improved mood, cognition, and overall quality of life. Research demonstrates that individuals with Parkinson's who participate in regular tango classes demonstrate significantly decreased depression and apathy. Tango offers an opportunity to take pleasure in the music, enjoy the company of your partner, and enjoy a sense of freedom. You have an opportunity to make new friends with other people taking the class strengthening your social network and increasing your self-esteem. There is no better sense of accomplishment than mastering a new dance step and being able to show it off to your new friends. Numerous studies even demonstrate that tango can result in improved cognition and decreased fatigue.

Uncertain whether you are ready for your first tango lesson? You're not alone. Taking a new dance class can be nerve-wracking for anyone. To ease your nerves, grab a friend or family member and bring them with you. The American Parkinson Disease Association – Greater St. Louis Chapter supports a special tango class just for people with a Parkinson's diagnosis held on Thursdays at 10:30 a.m. Register by calling the APDA Resource Center 636.778.3377. Classes are held at Convergence Dance and Body Center, 8044 Manchester Road in Brentwood, and are led by Carter Maier, professional dance instructor. They run in 10-week sessions (\$10 per class). Take the leap and try it out; you may end up with a new hobby! 🍷



Transform Your Body and Your Mind with Wendy Suzuki!

Photo of Dr. Suzuki speaking: Zach Dalin Photography



Wendy Suzuki, an internationally-recognized speaker and best-selling author of the book, *Healthy Brain, Happy Life*, was engaging and interactive as she empowered the audience at the Elliot and Mary Ann Stein Speaker Series, **now archived on our website**. The 400 guests attending the 2019 Stein Speaker Series left with an understanding of how aerobic exercise can improve learning, memory, and other cognitive abilities. We are deeply appreciative for the generous sponsors of this special annual speaker series, which is always open to the public: Presenting Sponsors—Jill, John, and Jim Stein; Silver Sponsor—RGA; and Bronze Sponsors—Ascension, James and Alison Bates Foundation honoring Nancy Rapp, Carol House Furniture, Clean Uniform, and the Staenberg Family Foundation.

In her presentation, Dr. Suzuki made neuroscience easy to understand, interweaving her personal story with ground-breaking research. She offered practical, short exercises to engage cognitively, improve memory, improve the ability to learn new skills, and to function more efficiently. We learned how neuroplasticity can change our brains, our bodies, and, ultimately, our lives. Thanks for all the valuable information, Dr. Suzuki! 🧠

Tributes & Donations

07.01.2019 to 09.30.2019

Every donation is greatly appreciated.

IN CELEBRATION OF

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Tricia Creel

Roger Decker

Brenda & David Andrews

Bill Fischer's Birthday

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Martha & Bourne Robards

Steve Hurster's Birthday

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Shirley & Jerrel Lewis

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We will be known forever by the tracks we leave...

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Marcia & Gaylen Evans
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Suzanne & Larry Hill
Beverly & Donald Hoke
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Georgia & Steve Lahay
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There are stars up above, so far away we only see their light long, long after they are gone.

**And so it is with people that we loved—
their memories keep shining ever brightly
though their time with us is done.**

**But the stars that light up the darkest night,
these are the lights that guide us.**

**As we live our days, these are the ways
we remember.**

—Hannah Senesh



It's One Hull of a Race!

Where in the world is Hull, IL? It's a little spot in the road just off of interstate 72 across the river from Hannibal, MO. In 2006, a physical therapist was treating two ladies from Hull who had been diagnosed with Parkinson disease. These energized women, plus their husbands and their therapist, decided to establish an annual race to raise money for Parkinson's research...and we're certainly thankful that they did! In 2019 alone, Hull of a Race raised \$12,500 to support Parkinson's research.

In 2011, this increasingly popular race resulted in a gift of \$10,000 for the APDA – Greater St. Louis, restricted for research. In 2012, "The Pit Crew" (formerly the committee) continued the tradition, sending in another \$10,000. And in 2013, they sent in another check for \$10,000. That was three years in a row!

Then 2014 rolled in with rain pouring through the night and during the race. There was no room for people to take shelter and it was very difficult to register runners. In spite of the rain and its impact on attendance, a check arrived in

the mail for \$9,000. What a testament to this community's commitment!

Each year, they continue to send \$10,000 or more to the APDA – Greater St. Louis Chapter to support research. In 2019, in loving memory of two founding members who passed away years ago and in memory of another original and devoted member who lost her brave battle with PD in February, the Hull of a Race organizers and Pit Crew were determined to work even harder to improve their race and raise more money for Parkinson's research.

Mission accomplished! Thank you to the many people who over fourteen years have succeeded in making Hull of a Race something to remember. This 14th year of the Hull of the Race was the best ever. With over 200 participants and in spite of a rainy night, more money was contributed in 2019 than in any other year to fight Parkinson disease...\$12,500!

Congratulations to Hull, IL, and everyone associated with this incredible community effort. 🌧️

MISSOURI SPEECH-LANGUAGE-HEARING ASSOCIATION COLLABORATION to Support Programs and Services

The American Parkinson Disease Association (APDA) – Greater St. Louis Chapter was the recipient of the Missouri Speech-Language-Hearing Association (MSHA) Cares Initiative when \$651.50 was raised at their annual convention. Their members felt a strong connection with the Greater St. Louis Chapter and wanted to help support individuals and families affected by Parkinson disease. Information about the APDA was shared with Convention attendees. MSHA was thrilled to not only raise money to help support our organization, but to also raise awareness of the programs and services we provide.

We know that this generous support will expand programs and services available to our constituents and are most grateful for being selected as the 2019 MSHA Care Initiative recipient. 🌧️



IMPROVE POSTURE AND FUNCTIONAL MOBILITY

Amy Counihan, DPT,
Medical University of South Carolina

If your muscles feel stiff or you sense that you're not standing as tall as you used to, you are not alone. Postural impairments are a hallmark of Parkinson disease and can result in changes such as decreased height and center of mass displacement. The typical postural changes seen with Parkinson's involve an individual's head coming forward, the shoulders and upper back rounding forward, and the trunk bending forward. All of these forward-directed postural shifts will cause the person's center of mass to shift forward from underneath the feet to past the toes. To feel more stable, the person may bend at the knees and the hips. While this helps with maintaining balance, it hinders functional mobility. Step length shortens resulting in shuffling steps, feet have difficulty clearing the floor, and more energy is required to walk. Lump these all together and you have the perfect recipe for an increased fall risk. These postural changes will also reduce the ability of the lungs to expand, resulting in softened speech, shortness of breath, and difficulty swallowing in more extreme cases.

Now you may ask, "Why can't I just straighten up and stop slouching?" There are two predominate reasons why: impaired proprioception and increased muscle rigidity. Individuals with Parkinson's commonly have impaired proprioception, or awareness of where their body is in space. Impaired proprioception is hypothesized to be due to impaired central sensory integration as a result of dopamine depletion in the basal

ganglia. This results in decreased limb and trunk positional awareness, causing decreased recognition of the postural changes occurring. Secondly, muscle rigidity is a very common Parkinson's symptom. Muscle rigidity is comparable to muscle tightness or inflexibility and is commonly seen in the arms and trunk. This results in an imbalance with the larger muscles overpowering the smaller ones. It may be seen on just one side of the body or both, and it can even affect the facial muscles, resulting in facial masking.

There are a number of steps you can take to improve your posture. First, you can participate in exercise classes hosted by the APDA - Greater St. Louis. All classes combine strength, flexibility, and cardiovascular activity with segments of every class aimed at improving posture. Tai Chi is particularly beneficial for postural improvement and is offered multiple times per week. Further, you can set up an appointment with a physical therapist, expressing your postural concerns. A physical therapist will be able to provide you with exercises that are appropriate, evidence-based, and safe for you as an individual to improve your posture. You can even make small environmental adjustments at home and work, such as ensuring that your computer and/or TV are at eye-level. If you prefer to read, invest in a bookstand to keep your novel at eye level. Check yourself out in the mirror a few times per day. Take a minute or two to think about where you are in space and adjust accordingly. Make this a habit and you'll be well on your way to improved posture and functional mobility! 🌊

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 Resource Center at 636.778.3377 or the facilitator at the number listed below. *Non-affiliated support groups are listed on our website only.*

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Ballwin	St. Louis	Meramec Bluffs Care Center 1 Meramec Bluffs Dr., Veterans Rm.	4th Tuesday	2:30 PM	Chaplain Chris Nilges	636.923.2338
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark St.	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 For Care Partners Only	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Jay Bender Lynda Wiens	636.778.3377
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Laura Sobba	636.931.7696 x148
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 1125 Madison St.	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 of Kirkwood 100 E. Adams Ave., Room 009, Lower Level	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW Patty Waller	314.286.2418
Rolla	Phelps	Phelps Health, 1000 W. 10th St. Private Dining Room #1	4th Thursday Nov mtg 3rd Thurs	2:30 PM	Karen Remillard	573.678.4649
South County	St. Louis	Tesson Heights 12335 West Bend Dr. Multipurpose Room	2nd Wednesday	10:30 AM	Caitlin Jones, MS, CCC-SLP	636.778.3377
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Jody Peterson, OTA Jessica Womack	636.724.4357
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Teddy Ross	618.210.7371
Trenton	Grundy	Royal Inn 1410 E. 9th St.	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283
Washington	Franklin	Washington Public Library 410 Lafayette Ave.	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

Please join us as we establish the Greater St. Louis

YOUNG ONSET PARKINSON DISEASE (YOPD) COMMUNITY.

*You had no choice
about the entrance of
Parkinson disease into
your life, but you DO have
a choice in how you will
live your life and what
your future will be.*

It is essential for younger people with Parkinson disease and their families to have updated information about the unique aspects of YOPD and have the opportunity to meet one another. Approximately 10-15% of people with PD in the United States fall into the YOPD category, defined as occurring between 21-50 years of age. Living with Parkinson's gets easier when individuals and families understand what's going on and can help one another.

Contact Angela Weaver at 636.778.3377 or
aweaver@apdaparkinson.org for more information.



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 Resource Center at 636.778.3377 or the facilitator at the number listed below. *Non-affiliated support groups are listed on our website only.*

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	Prairie Living at Chautauqua 955 Villa Ct. West building, 3rd floor	1st Wednesday (No meeting in December)	1:00 PM	Gala Lockwood	618.967.1317
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	217.854.3839
Centralia	Marion	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Betty Evans	618.533.0224
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Rd.	Every Monday	10:00 AM	Carol and Butch Clark Dave and Monica Matakas	217.898.2725 217.720.2016
Champaign—YOPD	Champaign	Scotty's Brewhouse 2100 Neil St.	1st and 3rd Tuesdays	6:00 PM	Laura Mock	217.781.0335
Charleston	Coles	LifeSpan Center 11021 E. Co. Rd. 800N	Last Tuesday	1:30 PM	Jean Shobe Jean Penrod	217.639.5150
Decatur	Macon	Westminster Presbyterian Church 1360 West Main St.	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Edwardsville	Madison	Edwardsville YMCA 1200 Esic Dr.	1st Tuesday	2:00 PM	Pam Pinegar Sara Hoelscher	618-656-0436
Highland	Madison	St. Joseph's Hospital, 12866 Troxler Ave, Sullivan Conference Room	4th Tuesday	2:00 PM	Kayla Toennies, OT Olivia Hodges, SLP	618.651.2720
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
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. St. #C	3rd Sunday, Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.814.8165
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

Illinois Exercise Classes

CITY	MEETING SITE	LEVEL	DAY	TIME	LEADER(S)	PHONE
Breese	Parkinson Pedalers (cycle + strength) Clinton County YMCA, 14160 Jamestown Rd.	Level 1	Monday Wednesday	2:00 PM	Jack Swank Vicky White	618.526.5628 (registration)
Carlinville	Movement Training Carlinville Area Hospital, Medical Office Building, Community Room, 20613 N. Broad	Level 1	Thursday	10:00 AM	Amy Murphy, PT	217.854.3141 x377
Champaign NEW!	Care Partners Small Group Training, Studio C Movement Training, Studio A Stephens Family YMCA, 2501 Fields South Dr.	All levels Level 1	Thursday	1:15 - 2:15 PM	Jenny Redden	217.239.6088 (registration)
Champaign NEW!	Tai Chi, Studio C Interval Training, Studio A Stephens Family YMCA, 2501 Fields South Dr.	All levels Level 2-3	Tuesday	1:15 - 2:15 PM	Jenny Redden	217.239.6088 (registration)
Champaign NEW!	Tai Chi, Studio C Parkinson Pedalers (cycle + strength), Studio A Stephens Family YMCA, 2501 Fields South Dr.	All levels Level 2-3	Friday	1:15 - 2:15 PM	Jenny Redden	217.239.6088 (registration)
Edwardsville NEW!	Movement Training Edwardsville YMCA, 1200 Esic Dr.	All levels	Tuesday & Friday	11:00 AM	Ann McLean	618.656.0436 (registration)
*Highland	Parkinson Pedalers (cycle + strength) Korte Recreation Center, 1 Nagel	Level 2	Monday Wednesday	11:00 AM	Jinee McDonnell-Stewart Ginger Kabureck	618.651.1386 (registration)
Jacksonville NEW!	Movement Training: All Levels Bob Freesen YMCA 1000 Sherwood Ln.	All Levels	Monday Thursday	3:00 PM 1:15 PM	Jennifer Smith Amy Little	217.245.2141 (registration)
O'Fallon	Parkinson Pedalers (cycle + strength) O'Fallon YMCA, 284 North Seven Hills Rd.	Level 1	Tuesday Thursday	12:00 PM	Amy Weisbrodt	618.628.7701 (registration)
Springfield	Joy of Movement (dance) First Presbyterian Church, 321 South 7th St.	All Levels	Tuesday Wednesday Thursday	1:30PM 10:00 AM 1:30 PM	Eve Fischberg, OT	217.494.4961

* This class has a fee for participation. If you have a need for a scholarship for any exercise class listed on this page that charges a fee, please contact the APDA – Greater St. Louis staff, as we have been fortunate to be recipients of donations to support and sustain these programs.

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



Missouri 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 select classes are available at all times on our website. **Exercise classes are one hour unless otherwise noted.**

CITY	MEETING SITE	LEVEL	DAY OF MEETING	TIME	LEADER(S)	PHONE
*Brentwood	Tango Convergence Dance and Body Center, 8044 Manchester Rd.	Level 2	Thursday	10:30 AM	Carter Maier	636.778.3377 (registration)
Chesterfield	Cardio + Strength 1415 Elbridge Payne, Ste. 163	Level 2	Wednesday	11:30 AM	Angela Weaver	636.778.3377
Chesterfield	Movement Training St. Luke's Outpatient Center, 111 St. Luke's Center Dr. Bldg. B, Ste. 14B	Level 1	Monday	10:00 AM	Ann Towey, PTA	314.205.6934 (registration)
Chesterfield NEW!	Chair Yoga and Meditation 1415 Elbridge Payne, Ste. 163	All Levels	Tuesday	1:30 PM	Ulrikke Malik	636.778.3377
Chesterfield	Movement Training 1415 Elbridge Payne, Ste. 163	Level 1	Monday Thursday	1:15 PM 11:30 AM	Tricia Creel, PT	636.778.3377
Chesterfield	Tai Chi 1415 Elbridge Payne, Ste. 163	Level 1 Level 2 Level 1	Tuesday Wednesday Friday	11:15 AM 10:00 AM 10:15 & 11:30 AM	Craig Miller	636.778.3377
Chesterfield	Parkinson Pedalers (cycle + strength) Chesterfield YMCA, 16464 Burkhardt Pl.	Level 2	Wednesday Friday	1:00 PM 12:30 PM	Michelle Valenti	636.532.3100 (registration)
Clayton	Fit 'n Fun The Center of Clayton, 50 Gay Ave.	Level 1	Wednesday Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Crestwood	Movement Training Charmette Academy of Dance 9901 Watson Rd. Ste. 125	Level 1-2	Thursday	1:50 – 2:40 PM	Teresa Godfrey, PT	314.942.5750 (registration)
*Creve Coeur	Roll With the Punches (boxing) The J's Stoenberg 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 NEW!	Parkinson Pedalers (cycle + strength) Kirkwood YMCA, 325 N. Taylor Ave.	Level 2	Tuesday	11:00 AM	Molly Yanics	314.965.9622
Ladue	Tremble Clefs Choir Salem United Methodist, 1200 S. Lindbergh Blvd., Lower Level Choir Room		Saturday	1:30 PM	Linda McNair, MT-BC	636.778.3377 (registration)
Maryland Heights	Movement Training Edward Jones YMCA, 12521 Marine Ave.	Level 1-2	Tuesday	12:00 PM	Martin Caupp	314.439.9622 (registration)
South St. Louis County	Parkinson Pedalers (cycle + strength) South County YMCA, 12736 Southfork Rd.	Level 1-2	Friday	10:30 AM	Diane Summers	314.849.9622 (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 Dr.	Level 2	Friday	10:00 AM	Marina Clements, PT	636.778.3377
St. Charles	Movement Training Windsor Estates Independent Living, 2150 West Randolph St.	Level 1	Tuesday	1:30 PM	Lacey Higgins, PT	636.946.4966
Ste. Genevieve	Movement Training Community Center, 21390 Hwy 32	Level 2	Thursday	11:00 AM	Ketta Hill, PT	573.883.9366
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	Rachel Lehman, OT	636.916.9650
*St. Peters	Aquatics St. Charles YMCA, 3900 Shady Springs Ln.	Level 1-2	Thursday	1:45 PM	Alicia Bunn, CTRS	636.896.0999 x21 (registration)
Town and Country	Tremble Clefs Choir Maryville University, 650 Maryville University Dr. Walker Building-Community Room		Thursday	1:30 PM	Megan Moran, MT	636.778.3377 (registration)
Washington	Parkinson Pedalers (cycle + strength) Four Rivers YMCA, 400 Grand Ave.	Level 1	Tuesday Friday	1:00 PM	Brandy Koch	636.239.5704 (registration)
Wildwood NEW!	Parkinson Pedalers (cycle + strength) Wildwood YMCA, 2641 Highway 109	Level 2	Tuesday	11:00 AM	Lynn Kelly	636.458.6636

* This class has a fee for participation. If you have a need for a scholarship for any exercise class listed on this page that charges a fee, please contact the APDA – Greater St. Louis staff, as we have been fortunate to be recipients of donations to support and sustain these programs.

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

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Just call **636.778.3377** or email **apdastlouis@apdaparkinson.org** to keep us updated.

Thank you in advance for helping us spend our resources wisely!

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SAVE *these* DATES IN 2020!

Midwest
Parkinson
Congress



MAY 7

Midwest Parkinson Congress to be held at Logan University

JUNE 7

Elliot and Mary Ann Stein
Speaker Series featuring
JOHN O'LEARY,
author of *On Fire*, who will
celebrate and share his new book
to be released in May, 2020,
***IN AWE: Rediscover Your
Childlike Wonder to Unleash
Inspiration, Meaning, Joy.***

MAY 18

APDA Annual
Golf Tournament
in Memory of
Jack Buck held at
Algonquin Golf Club

