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GREATER ST. LOUIS CHAPTER

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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.

Past-Present-Future

Debbie Guyer, Executive Director

Welcome!



Terri Dietrich



Angela Weaver



Melissa Palmer

This year has brought numerous changes for the APDA – Greater St. Louis Chapter and will continue to be a transition year with more changes slated to occur in January. Many of you have inquired about the new faces at the Center, so let me introduce you to our staff. **Terri Dietrich** joined our staff recently as the new Office Coordinator. Terri comes from the Chesterfield YMCA where she served as Lead Member Service Associate. You will enjoy meeting Terri, as she answers the phones or greets you as you enter the Center.

Amanda Landsbaum will continue to offer Wellness Courses twice a year, but has chosen to leave her part-time staff position and is already missed. **Angela Weaver** may be known to many of you from the Chesterfield YMCA as their Health and Wellness Director. Angela was involved in initiating our Parkinson's exercise classes there, and has joined us in a full time position as Program Coordinator. Angela will coordinate the support groups throughout the bi-state region in addition to having a role in the Time Matters program, PD101, and other activities. **Tricia Creel** will work three days a week, continuing in her role as Program Coordinator, providing exercise classes at the Center, the Freezing of Gait Boot Camp, the new Driver Retirement Workshop, and other wellness programming. You may already be receiving acknowledgements from **Melissa Palmer** (Mel) who joined our Chapter in a new position as Development Coordinator. Mel manages our website and has edited newsletters in her previous positions in Nebraska, so you will see her influence on many of the things you receive. **Melissa Skrivan** joined us last October as Director of Development and has taken charge of fundraising, grant writing, creation of invitations and program booklets, and assists me in many other duties.

>> *Continued on page 12*

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



Pull up a chair, whippersnapper, old Parkie Pete is about to regale you with some Parkinson's wisdom! I have been wandering in the Parkinson's desert for 17 years since my diagnosis in 2002. (It's actually been longer than that, as there is a decade or so when Parkinson's affects you but is not diagnosable.) My wanderings have been driven by the search for credible hope.

So what is "credible hope"? It is the difference between hope and hype, the conviction, rooted in reality, that it is within your power to significantly improve your quality of life with Parkinson's. This is more than the casual, well-meant-but-questionable assertion that the cure is just around the corner, or ten years down the road. I have Parkinson's today and must deal with the falling, the drooling, the speech impediments, the cramping muscles, the tremor, depression, etc...today and every day until a cure, or something like a cure, is found.

What is "credible hope"?
It is the difference between
hope and hype, the
conviction, rooted in
reality, that it is within
your power to significantly
improve your quality
of life with Parkinson's.

It is an irony of credible hope that it must be admitted how difficult it is to unravel the mysteries of Parkinson's. You won't be fooling anybody if you don't cop to the gravity of the situation and admit the difficulty involved in the undertaking. This admission not only enhances the credibility of your hope, it also makes you more aware of the magnitude of what has been accomplished so far, and the distance we have come in just the past few years.

So let's stipulate that for the thousands of years that humanity has suffered from Parkinson's we have found little that can alleviate the symptoms, let alone cure Parkinson's. It is a formidable disorder.

Depressing? No. Not when you consider that the discovery of Parkinson's therapies and understanding of the way it affects those of us who must cope with it have been coming (relatively) thick and fast in the last half century. (OK, maybe just a wee bit depressing.)

The Parkinson's landscape I encountered back in 2002 was a bleak one, featuring inevitable progression of symptoms, leading inexorably to disability in 10 to 15 years. Available treatments could only give symptomatic relief and only for a while, until the effects of the treatment became worse than the disease. And, worst of all, the helplessness of the person with Parkinson disease to do anything substantial to ward any of these miseries off.

Trust me, I turned over every rock I could find, and came up with nothing but beetles, grubs, ants, and worms.

The landscape has transformed in the short time since I was diagnosed. You want credible hope? Here is a list of things I benefit from every day that were not on the radar, or were only blips on the fringe of Parkinson's knowledge, back when I was diagnosed.

>> *Continued on page 12*



Swinging into Action for the APDA 21st Annual Golf Classic IN MEMORY OF JACK BUCK

Breaking Last Year's Fundraising Record!

The APDA Golf Classic in Memory of Jack Buck was THE ticket to have again this spring! The tournament, held annually in May to support local Parkinson's programs, services, and research, was sold out before the invitations were even mailed in March. We are deeply grateful to participants who enabled us to raise over \$211,000, a new record for any single fundraising event hosted by the Greater St. Louis Chapter since we were chartered in 1984. We will be able to help the growing number of people with Parkinson's, their families and care partners because of the generosity of those supporting this event.

The golfers enjoyed a perfect day on the greens – cool temperatures, low humidity and sunshine. Dinner guests enjoyed a reception with hors d'oeuvres and an open bar, a question-and-answer session with John Mozeliak, President of Baseball Operations for the St. Louis Cardinals, and Tom Ackerman, Sports Director for KMOX radio, and a delicious surf-and-turf dinner prepared by Chef Bernstein at Algonquin Golf Club.

Highlights of the evening included:

Guest speaker, Cathy Combs, who described the trajectory of life after receiving a diagnosis of Parkinson's at a young age, her hopefulness, and the benefits derived by participating in programs and services offered at the APDA Resource Center. She is most grateful to have a long future to look forward to and reminded us of Michael J. Fox's comment, "Look at the choices you have, not the choices that have been taken away from you. In them, there are whole worlds of strength and new ways to look at things!" She thanked the audience for their support – and support they did!

A successful **auction** featuring unique gifts donated to the Chapter that raised **\$17,350**, led by our eminent auctioneer, Tom Ackerman.

Our guests contributing exceptionally to Fund-a-Need, raising an incredible **\$51,428** to support the quarterly *LiNK* newsletter, Midwest Parkinson Congress, Parkinson Education Programs, Freezing of Gait Boot Camp, support groups, Tai Chi and assorted exercise classes which are live-streamed and archived on our website, PD101 sessions, and the Advanced Center for Parkinson Research at Washington University School of Medicine.

Our success is impacted by the **generosity of our sponsors** who contributed **\$95,500** this year. Many of these are returning sponsors who continue to increase their support year after year. We encourage you to express your thanks when supporting their businesses and recognize their outstanding contributions to our community.

From top to bottom: Guest Speaker Cathy Combs; Matt Schumacher; Ryan and Lindsey Carlie



PRESENTING SPONSOR (\$25,000): James & Alison Bates Foundation in honor of Nancy Rapp; **MASTERS SPONSOR (\$10,000):** Carol House Furniture; **MAJOR SPONSORS (\$5,000):** BurkHill Real Estate (Mark Burkhart), Dowd Bennett LLP, Scott G. Lentin Fund, Luxco, Moneta; **GOLF CART SPONSORS (\$3,500):** Fairlie Law LLC, KPMG; **CONTEST SPONSORS (\$3,000):** Boston Scientific, Legacy Pharmaceutical Packaging, Morgan Stanley (John D. Buck); **COCKTAIL RECEPTION SPONSORS (\$2,000):** Budget Billboards & For Pete's Sake, Sandy & Rob Goren, Lynn & Steve Hurster, St. Louis Cardinals; **GOLF SHIRT SPONSOR (\$2,000):** Wunderman; **BEVERAGE & SNACK SPONSOR (\$1,500):** Barry Roufa; **PRACTICE AREA SPONSORS (\$1,000):** Jean & John Basilico, Husch Blackwell, Medtronic; **HOLE SPONSORS (\$500):** Assistance Home Care, Axiom, Don Carlson, The Delmar Gardens Family, The Elder & Disability Advocacy Firm of Christine Alsop, Ted Hume, Ashley & Matt Specter, Shillington Box Company, Jack Strosnider, Western Oil Inc. Our **EXCLUSIVE RADIO PARTNER:** KMOX NewsRadio 1120 enabled us to market and promote the golf tournament at the St. Louis Cardinals Spring Training, helping raise awareness of the APDA and Parkinson disease.

AUCTION/IN-KIND DONATIONS: Tom Ackerman & KMOX, Algonquin Golf Club, Autohaus BMW, Blues for Kids Foundation, The Clover and the Bee (Mark Hinkle), Fastsigns of Bridgeton, FlightSafety International, Four Seasons St. Louis, Golf Discount, Maryville University, Mister Guy Clothiers, Terese & Bob Mitchusson, John Mozeliak, Niche Food Group, Noboleis Vineyards (Lou Ann & Bob Nolan), Poppy & Pine, Pretzel Boy's, The Ritz-Carlton St. Louis, Rock Steady Boxing Chesterfield (Carolyn McKee), Barry Roufa, Seeger Toyota, Slay Industries (Gary Slay), Mary Strauss, St. Louis Blues, St. Louis Cardinals, Tom James Clothiers, Truffles in Ladue.

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Special recognition to our returning hard working **VOLUNTEERS** who assisted us during the day from Edward Jones and our APDA Golf Classic volunteers who assisted during the auction and Fund-a-Need evening activities: Lisa & Keith Ackerman, Charlene Allo, Katie Benjamin, Robert Carroll, Linda & Ed Dahl, Rebecca Farris, Eli Glass, Karl Guyer, Brian Hantsbarger, Stacey & Steve Kohner, Joyce & Benjy Levin, Annie Marshall, Robin & Craig Miller, Angela Nieman, Sarah Schmerber, Grant Sjurson, Ashley & Matt Specter.

We can't forget to thank our **112 golfers** who had a great day on the greens, bidding charitably with our dinner guests on the unique and much-sought-after auction items, enjoying the question-and-answer session with John Mozeliak and Tom Ackerman, and feasting on the delicious dinner Chef prepared.

If you are interested in serving on our 2020 golf committee or wish to receive a save-the-date and invitation to next year's golf tournament to be held on Monday,

May 18, 2020, at Algonquin Golf Club, let us know by phone: 636.778.3377 or email: apdastlouis@apdaparkinson.org. We look forward to setting another record-breaking year at this always sold out event!



Above, from top: APDA Staff at Registration; Chuck Fandos & John Hogan; Tom Ackerman & John Mozeliak; Standing: Larry & Amy Lentin, Debbie Mahler, Stan & Sally Zimmerman, Beverly Friedman & Avery Seidel, seated: Joe Ryan, Art & Margie Silverblatt, Terry Friedman

How to Bring Light to the Darker Side of Parkinson's:

A Primer on Hallucinations and Delusions and How to Manage Them

Continued from an article that appeared in the May 2019 LiNK, pages 4-5



How to care for someone who experiences hallucinations:

If the person you care for experiences a hallucination, there are a few things you'll want to do in the moment and others you'll want to do when the moment passes.

The most important thing to remember is to never try and talk the person with Parkinson's out of their hallucination. They are actively experiencing it, and by trying to talk them out of it, they may either feel like they aren't being heard or that their experience is being diminished.

What matters in the moment is their safety and your reassurance that they're going to be okay. You might calmly say, "I understand that you're seeing X. I'm not having that experience, and I just want you to know that everything is going to be okay, there's nothing dangerous happening here, and you're safe."

Other strategies:

- » Turn on all the lights to make the room as bright as possible, as hallucinations often happen in low lighting.
- » Have the person look closely at what they're seeing as that can help reset the brain and make the hallucination end.
- » If the person does not have insight, give them reassurance, provide a distraction, move into a different room, or suggest a new activity.

Here are a few actions you can take once the hallucination has passed:

- » Talk to the person about it. Most of the time, even if the person does not have insight, they will remember when it's over.
- » Tell their doctor and offer as much detail about the episodes as you can remember, including time of day,

- location, and anything else that may have had an impact on the situation (i.e., the person's fatigue, hunger levels, etc.).
- » Be sure to keep light switches in convenient locations. Since waking up and going to bed are the most prevalent times for people with Parkinson's to have hallucinations, turn lights on as soon as you wake up and make sure they're bright.
- » Eliminate/reduce shadows in the house, and be careful where you place mirrors and reflective surfaces as they can play games with the mind.
- » Investigate any environmental triggers that could be causing hallucinations with more frequency or regularity.

How to care for someone who experiences delusions:

If the person you're caring for experiences delusions, here's what you can do in the moment:

- » Stay as calm and as patient as you can, and remember that this belief has nothing to do with you and only with what is going on in your loved one's mind.
- » Remove any objects in the room that could pose a danger to them or to anyone else.
- » Clear space so there are no tripping hazards and it's easy for the person to move around.
- » Do not try to reason with the person or convince them why their belief is false.
- » Reassure them that everything is going to be okay.
- » If the person becomes aggressive, minimize your movements and remain calm.
- » Ask the person to talk to you about what they are feeling and really listen to them so they don't feel threatened.
- » If you feel like you or they are in danger, call 911.

>> Continued on following page

Here are a few actions you can take once the delusion has passed:

- » Inform the doctor immediately.
- » Educate others who may care for the person how to handle the situation if it happens.
- » If the person is open to it, discuss it with them and ask them to explain what the experience is like for them and if there's anything different you could do next time.
- » Seek expert advice if you feel like you need support in managing these episodes.

Bringing light to the darker side of Parkinson's:

Often the hardest part of Parkinson Disease Psychosis (PDP) is the fear of the unknown. As a person with Parkinson's, you may worry about having hallucinations and/or delusions and not being able to do anything about it. As a care partner, you may worry that you won't be able to help the person with Parkinson's feel safe if something does happen.

The good news is you now have information on what

PDP is, the risk factors, biological and environmental triggers that can bring an episode on, and how to manage a psychotic episode if it occurs.

But what about the emotional toll of these types of symptoms over the long term

If you or a loved one is living with PDP, please work closely with your Parkinson's doctors to assess your unique situation and create a treatment plan that's right for you.

as the person with Parkinson's or as a care partner? The diagnosis of a chronic illness in and of itself requires a lot of adjustments. When you add something like PDP into the mix, it's important that you also add another level of self-care into your everyday life.

Self-care for the person with Parkinson's:

- » Join a Parkinson's support group if you don't already belong to one. Talk about your experiences, ask for help if you need it, and share what's worked and not worked for you. (See a listing of the support groups we offer on pages 13-14 of this newsletter.)
- » Offer to have coffee with someone who is newly diagnosed and offer them support and encouragement. There's nothing more effective for getting out of our own lows than to find someone else to help.
- » Make time to exercise.
- » Communicate frequently with your doctors and discuss the possibility of changing your medications if your symptoms become worse.
- » Rest when you need it.

- » Take control where you can and keep authoring your own story.
- » Practice meditation, yoga, or Tai Chi to relax and calm your mind.
- » Start a new project that you're excited to work on every day.
- » Communicate with your care partners and let them know how they can best help you.

Self-care for the care partner:

- » Join a Parkinson's care partner support group. Talk about your experiences and ask for help if you need it.
- » Allow others to help you care for your loved one with Parkinson's. Take breaks. Connect with the person you are aside from being a care partner.
- » Do activities you love and that help you keep your mind off your role as a care partner.
- » Get a treatment you love such as a massage or go to a yoga class, run, or play tennis. Whatever it is, do something that brings you joy every day.
- » Seek therapy or counseling if you want extra support.
- » Identify people in your life you can trust and share your experiences with them. You don't have to take all of this on by yourself.
- » Be open to what may be the next steps for you and the person with Parkinson's...even if it's not what you imagined. One of the most common reasons for nursing home placement for people with Parkinson's is non-remitting psychosis. If it gets to be too much for you to manage on your own, consider potential arrangements that would be best for everyone.
- » Keep an open line of communication between you and your loved one's Parkinson's care team, and don't be afraid to ask for information, help or resources.

WHAT'S NEXT?

If you or a loved one is living with PDP, please work closely with your Parkinson's doctors to assess your unique situation and create a treatment plan that's right for you. No two people experience PDP in the same way, so it's critical to understand and evaluate all of your potential options. Throughout the process, be sure to make note of how you feel, how you behave and how medications or therapies are impacting you on a regular basis so your doctors and care partners can keep an up-to-date record of your experience.

This article was written by the Davis Phinney Foundation and published on their blog along with their thanks to Drs. Mark Mapstone, Joanne Hamilton, Daniel Weintraub, and several people with Parkinson's and their care partners for their expert guidance in writing the article.

It is reprinted here with their permission.



**AMERICAN
PARKINSON DISEASE
ASSOCIATION**

Help Us Beat Parkinson Disease— One Step at a Time!


Join us for the 3rd Annual APDA Optimism Walk on Saturday, October 19, at Logan University.

The Optimism Walk is a short, non-competitive walk with family-friendly activities that is part of a nationwide movement to mobilize and inspire people to step up and put an end to Parkinson disease.

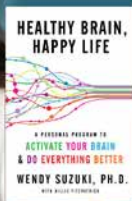
Each year, the Greater St. Louis Chapter serves more than 12,000 people impacted by Parkinson disease through support groups, exercise classes, wellness programming, educational events, and more. Your support of the Optimism Walk helps ensure these programs and services are there for people when they need them the most.

We will assemble at Logan University in Chesterfield, MO, at 9:30 a.m. to kick off the event with team photos, face painting, balloon twisting, visits to sponsor and vendor booths, and more. The walk will begin at 10:30 a.m. followed by time for refreshments and announcements of our raffle winners.

Sign up today at 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!



Join us to learn the important role exercise plays in neuroplasticity and expanding cognitive reserve.



Tickets are \$20 and seating is limited.

Reserve your spot today!

“The constant interaction between the brain and the environment, combined with the brain’s ability to respond by changing its anatomical structure and physiology, is what scientists mean by the term brain plasticity. Stimulate the brain with new things to do or new individuals to interact with and it reacts by creating new connections that cause it to actually expand in size. But deprive your brain of new stimulation or bore it with doing the same thing day after day, and the connections will wither away and your brain will actually shrink.” – Wendy Suzuki, Ph.D. (Excerpt from *Healthy Brain, Happy Life*)

STEIN SPEAKER SERIES *featuring* **WENDY SUZUKI, Ph.D.** **ON SEPTEMBER 8**

What’s the most transformative thing that you can do for your brain today? “Exercise!” says neuroscientist Wendy Suzuki, Ph.D. Attend the Stein Speakers Series program at 3:00 p.m. on September 8 at Congregation Shaare Emeth to understand the science behind exercise and how it boosts your mood and memory—and protects your brain against neurodegenerative diseases. You will be inspired by Dr. Suzuki’s energy as you learn the life-changing effects that physical activity can have on the most important organ in your body: your brain.

Tickets are \$20 per person and seating is limited. Register today at www.apdaparkinson.org/greaterstlouis or by calling 636.778.3377.

Tributes & Donations

04.01.2019 to 06.30.2019

Every donation is greatly appreciated.

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Terri & Bill Taylor

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Or use the donation envelope in
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Do-it-yourself Fundraising

Throw a party to honor a loved one
 impacted by Parkinson's, such as the
 Pictures for Parkinson parties.

Ask friends to support an adventure,
 such as the Tractor Cruise,
 Hull of a Race, or RAGBRAI bicycle ride.

Plan a bake sale or yard sale
 and donate the proceeds to APDA.



DO IT YOURSELF OPTIMISM EVENT

REPRISE OF

PEDALING 4 PARKINSON'S

in Aviston, Illinois

On Saturday, June 8, 2019, at Vintage Hall in Aviston, IL, 200 bike riders and walkers took to the streets for **Pedaling 4 Parkinson's**. This is the second year Lynn Huegen and her committee have organized this event in honor of Lynn's father. Riders were able to participate in 10- or 25-mile routes. They also offered a one-mile family fun bike ride or walk route. **Thanks to amazing community support, they were able to raise \$11,423.35!** Following the ride, participants enjoyed festivities, food, and drinks at the Aviston Block Party. Lynn and her committee were motivated to fundraise in honor of her dad and family and friends of committee members who are battling Parkinson disease. Raising awareness resulted in many others in the community sharing and revealing their own Parkinson connections.



PREMIER DRIVING RETIREMENT WORKSHOP

HISTORY WAS MADE in June at the APDA – Greater St. Louis Chapter when participants completed the first workshop to help people with Parkinson disease and their families plan for retirement from driving. The ability to drive can have a large impact on a person's independence, participation in activities, and sense of self-worth. When someone has been driving safely for many years, it can be very hard to determine when to retire the keys. Living with Parkinson disease can mean changes in motor and cognitive abilities, some of which may affect a person's ability to drive safely. As a result, the APDA – Greater St. Louis Chapter felt it was important to offer a program to help people approach this often sensitive and stressful process armed with knowledge and a plan.

Nine participants with Parkinson's and their accountability partners attended the Driving Retirement Workshop which covered the following:

- » How Parkinson's can affect someone's ability to drive and signs of unsafe driving
- » Options to assess safety while driving
- » Local transportation resources
- » Creation of a personalized driving retirement plan

Participants had a chance to work in small groups, ask questions, and even get help downloading new applications to use on their smart phones. The workshop addressed a serious topic, but the group still managed to have fun, even sharing light-hearted stories about their experiences learning to drive.

The workshop was made possible by a generous grant from the JCA Charitable Foundation and was developed and delivered in partnership with Peggy Barco, OTD, OTR/L, SCDCM, CDRS, FAOTA, Assistant Professor of Occupational Therapy and Medicine at Washington University. Dr. Barco directs the Driving and Community Mobility Laboratory, and her research focuses on driving performance in older adults with medical impairments. Occupational therapy students from the lab worked under Dr. Barco's direction to help create and deliver the workshop. One of the highlights of the workshop was a humorous video the students created to demonstrate how to use ride-sharing services.

Another session of the Driving Retirement Workshop will be held in the fall of 2019 at the APDA Resource Center in Chesterfield. To register or for more information, call 636.778.3377.

>> *Continued from page 2*

1. Deep Brain Stimulation (DBS). I know, I know, it's brain surgery, and not for everyone, but it gave me a new lease on life, and, among other things, dealt completely with my tremor and enhanced my nightly sleep. For a man living on borrowed time, it significantly raised the limit on time I could borrow.
2. Imbalance, once a ferocious and intractable feature of Parkinson's, now is understood to be mitigated through balancing activities, like Yoga or Tai Chi. Do I still fall? Yes, but I am sure that the frequency of these nasty episodes is down significantly from where it would be without daily balance practice.
3. REM sleep disturbance, the phenomenon that allows people with Parkinson's to act out their dreams physically, leading to falling out of bed and assaults on your bed partner, can be limited by taking melatonin and you are much less likely to rain hammer blows on your beloved. What's not to like?
4. Moderately intense exercise can reduce your motor symptoms by 30%, as per the research done by Jay Alberts on the effects of forced exercise. He explains it better than I can here: <https://www.davisphinneyfoundation.org/blog/podcast-how-to-exercise-live-better-with-parkinsons-with-dr-jay-alberts/>.

This is one of the things that is most significant in the recent history of Parkinson's research. Why? Because of the leverage it gives the individual person against

Parkinson's. You don't have to have exercise prescribed (although it is wise to talk it over with your movement disorder specialist), it doesn't cost much, it's not that hard to do, and it is effective in coping with Parkinson's symptoms and possibly rewiring the brain so that it functions better.

5. It is now clear that the sooner you adopt any of several significant Parkinson's interventions, taking levodopa, exercising regularly, and DBS among them, the slower your progression to disability will be.

These are things you can do today to make your quality of life higher, without waiting for new miracles to deliver you from the clutches of Parkinson's. My hope now is that you act.

As many of you know, I am a big fan of Peter Dunlap-Shohl. Peter has a wonderful way of capturing the essence of his feelings mixed in with a sense of humor, and over the years, I've requested his permission and that of the Northwest Parkinson Foundation (NWPFF) to reprint his blog or "ruminations" about Parkinson disease. The June posting that I have shared with you resonated with me as I reflect during my PD101 sessions about "credible hope" – the kind of hope that can be shared with those of you who are newly diagnosed. Peter reminds me and you that even if you've traveled on this journey for over a decade there is still credible hope as you look back on developments which have occurred since you were initially diagnosed and the work that is being done on a daily basis to find a cure and to improve your quality of life as you face the challenges of this disease.

– Debbie Guyer

>> *Continued from front page*

An announcement was made at the Golf Classic in May confirming my retirement on January 10, 2020.

A national search for my successor has been initiated by our home office, and I look forward to mentoring new staff in my final months with the Greater St. Louis Chapter as well as passing the baton to the individual selected to replace me as Executive Director of this Chapter. You have enabled me to grow and to learn and to age in place! One

of my favorite things has been getting to know so very many of you over my tenure with APDA. I started my service on the APDA Board of Directors in 1997 and served on the board for 10 years (presenting LSVT to groups, facilitating an adult children of parents with PD support group, chairing a health fair at Ladue High School, and working with patient programs). From there, I joined APDA as Information and Referral Coordinator in our host institution, Washington University School of

Medicine, following in the footsteps of Susan Levin, who built this Chapter over her 25-year tenure with APDA. I look forward to being actively involved with the two PEP meetings scheduled for the fall, the Stein Speaker Series, Optimism Walk, and the end-of-year campaign. That will give me an opportunity to see all of you before my departure in January, so don't be a stranger! We have wonderful events occurring every month through the end of the year.



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 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
Ladue	St. Louis	The Gatesworth 1 McKnight Pl., Lower level	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 Health, 1000 W. 10th St. Private Dining Room #1	4th Thursday Nov mtg 3rd Thurs	2:30 PM	Sarah Robinson	573.201.7300
South County	St. Louis	Tesson Heights (beginning 09/11/19) 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

Tremble Clefs choirs, directed by Linda McNair, MT-BC and Megan Moran, MT-BC, performed on June 30, 2019. The concert is available for viewing on our website. Special thanks to Mr. Richard Winter & Garden View Care Center, for the generous grant supporting the Tremble Clefs choirs this past year.



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

Illinois Support Group Calendar

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CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Alton	Madison	Senior Services Plus, 2603 N. Rodgers Ave.	3rd Tuesday	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	1:00 PM	Bill Hamilton, MD	618.339.4159
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 Helena Quaid	618.533.0224 618.493.6064
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
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
Nashville	Washington	Washington County Hospital 705 S. Grand Ave., Conference Room	4th Friday	1:00 PM	Helena Quaid	618.493.6064
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
Quincy For Care Partners Only	Adams	Quincy Public Library 526 Jersey St.	2nd & 4th Tuesdays contact leader to verify date and time	12:30 PM	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	Interval Training Stephens Family YMCA 2501 Fields South Dr.	Level 2-3	Tuesday	1:15 – 2:30 PM, Studio A (registration required)	Drew Earls Jenny Redden	217.239.2850 217.239.6088
Champaign	Movement Training Stephens Family YMCA 2501 Fields South Dr.	Level 1	Thursday	1:15 – 2:30 PM, Studio A (registration required)	Drew Earls Jenny Redden	217.239.2850 217.239.6088
Champaign	Parkinson Pedalers (cycle + strength) Stephens Family YMCA 2501 Fields South Dr.	Level 2-3	Friday	1:15 – 2:30 pm in Studio B (registration required)	Drew Earls Jenny Redden	217.239.2850 217.239.6088
Edwardsville	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	Movement Training: All Levels Bob Freesen YMCA 1000 Sherwood Ln.	All Levels	Monday Tuesday Thursday	3:00 PM 1:15 PM 1:15 PM	Jennifer Smith	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

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	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 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)
Crestwood	Movement Training Charmette Academy of Dance 9901 Watson Rd. Ste. 125	Level 1-2	Thursday	1:45 PM	Teresa Godfrey, PT	314.942.5750 (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
*Creve Coeur	Roll With the PUNCHES (boxing) 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
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)
O'Fallon	Movement Training Park Place at WingHaven, Independent Living Fitness Room, 2002 Boardwalk Place Dr.	Level 1	Wednesday	10:00 AM	Colleen Bock, PTA	636.233.2813
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
*South St. Louis County	Roll with the PUNCHES (boxing) HouseFit, 3809 Lemay Ferry Rd.	Level 2-3	Tuesday & Thursday	11:00 AM	Marina Clements, PT	314.339.7430 (registration)
St. Charles	Movement Training Windsor Estates Independent Living, 2150 West Randolph St.	Level 1	Tuesday	10:00 AM	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	Tim Peters	636.239.5704 (registration)

* 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.

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 keep us updated.

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

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AUGUST 24

**The annual Mid-Missouri
Parkinson's Disease Patient
and Caregiver Conference**

The annual Mid-Missouri Parkinson's Disease Patient and Caregiver Conference, put on by MU Health Care, will take place in Columbia, MO, at the Holiday Inn Executive Center. Exhibits will start at 8:00 a.m. and the program will start at 8:30 a.m.

SEPTEMBER 8

**The Elliot & Mary Ann Stein Speaker
Series featuring Wendy Suzuki, Ph.D.**

NYU neuroscientist and author of *Healthy Brain, Happy Life*, will address exercise, neuroplasticity, and how to expand your cognitive reserve. The program will be held at 3:00 p.m. at Congregation Shaare Emeth, and tickets may be purchased online or by calling the Resource Center at 636.778.3377.



AMERICAN
PARKINSON DISEASE
ASSOCIATION

OCTOBER 19

**Optimism Walk
Logan University**

This fun, family-friendly event provides participants with a short walk, vendor booths, raffle, activities for kids, and time to visit and meet others who have Parkinson disease. Registration begins at 9:30 a.m., and the walk will start rolling at 10:30 a.m.

NOVEMBER 3

**New information
and options for
the treatment of PD
using Deep Brain
Stimulation (DBS)**

PEP sharing new information and options for the treatment of PD using Deep Brain Stimulation (DBS). This program features a panel of physicians (including neurosurgeons and movement disorder specialists) and individuals who have undergone this procedure and can share their personal stories. This program will be held in the Kehillah Center at Congregation Shaare Emeth and will start at 2:30 p.m.