

IN THIS ISSUE

From A Child's Perspective - Through The Decades	1-2
No Greater Gift	3
Determining What Type Of Care Is Needed	4-5
Golfers Swing Into Action For Parkinson's	6-7
Be A Cyclestar At The Cyclebar	7
Midwest Mini-Parkinson Congress	8
Family Fun At Inaugural Optimism Walk - Party With A Purpose!	9
Tributes And Donations	10-12
Optimism Events	12
Support Group Calendars	13-14
Exercise Class Calendar	15
Got Internet?	16
Website Notice	16
Save The Date	16

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
GREATER ST. LOUIS CHAPTER

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

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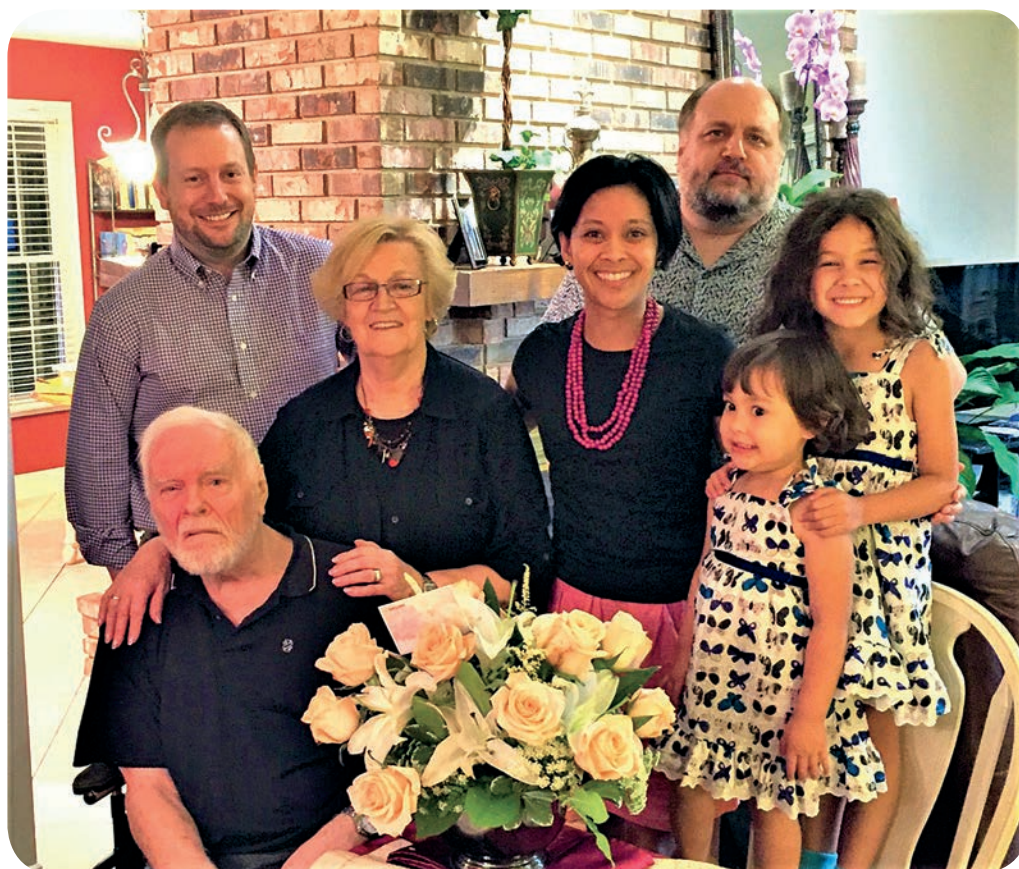


OUR MISSION

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

FROM A CHILD'S PERSPECTIVE - THROUGH THE DECADES

GRANT WIENS



Grant, Lynda, Robyn, Garth, Eve, June and Bob

I've thought about what I was going to say at my dad's funeral for a long time.

My dad was diagnosed with Parkinson disease when I was starting middle school, almost 30 years ago. I'm about to turn 40 now, so for most of my life, my dad has been sick. One of the many crummy things about the disease is that each person has a different horizon. You know it will be downhill, but you don't know how long or how steep. We didn't know if my dad would still be alive in 5 or 10 or 15 years. Trying to cope with that uncertainty, I would imagine

at different points in my life what I would say at my dad's funeral if he died right then.

So, when I was a teenager in high school, I imagined standing at my dad's funeral and talking about how his struggle with Parkinson's taught me perspective. I watched a man in his 40's go from walking to stumbling to using a cane. My mom and I needed to help him in the morning with buttons and shoelaces. He dutifully monitored his medication, taking less at night and more during the day so that he could stay productive at work. The trade-

continued on next page

APDA GREATER ST. LOUIS CHAPTER

Deborah Dalin Guyer, MA
Executive Director
dguyer@apdaparkinson.org

Sarah Schmerber, OTD
Program Director
sschmerber@apdaparkinson.org

Tricia Creel, PT, DPT, NCS
Wellness Program Coordinator
tcreel@apdaparkinson.org

Mike Garavalia
Campaign Manager
mgaravalia@apdaparkinson.org

Meredith Wallus
Office Coordinator
mwallus@apdaparkinson.org

APDA COMMUNITY RESOURCE CENTER

1415 Elbridge Payne ■ Suite 150
Chesterfield, MO 63017

Hours: 7:30 a.m. – 4:00 p.m. M–F
Phone: 636.778.3377

www.stlapda.org

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Joel S. Perlmutter, MD

NATIONAL AFFILIATION

APDA ■ 135 Parkinson Ave.
Staten Island, NY 10305
800.223.2732

EDITOR

Deborah D. Guyer

CONTRIBUTING EDITORS

Tricia Creel
Mike Garavalia
Betty Hayward
Sarah Schmerber

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.

FROM A CHILD'S PERSPECTIVE - THROUGH THE DECADES

continued from page 1

off was terrible dyskinesia and dystonia, debilitating episodes that kept him awake for long stretches every night and that forced him many days to lie down on his office floor in exhausting pain for hours at a time.

And, when I was in my early 20's finishing college, I imagined talking at my dad's funeral about how his struggle with Parkinson's taught me resilience. Steadily, the disease took away the things my dad loved to do, but he remained determined to find new ways to keep enjoying them. When he canceled his Blues season tickets because he couldn't get himself into the Arena any more, he watched every game at home and yelled loud enough for the ref to hear him through the TV. When he had to stop going out onto the golf course, he became the rare father who played more video games (always golf) than his kids. And, when he had to stop teaching medical students and seeing his patients in the hospital, he still found a way to teach and care for others. He and my mom got involved with the APDA, developing, attending and leading support groups, thereby helping people learn how to live with their new and continuing diagnosis. He also got back to teaching med students, speaking at one lecture a year to offer a patient's perspective on his neurological disorder.

When I was in my early 30's getting married, I imagined talking at my dad's funeral about how his struggle with Parkinson's taught me the importance of family. Stuck with a walker and wheelchair, he suffered an incredible amount of pain to visit me in Seattle, my brother in Boston and his siblings in Canada. He spent months and months in front of the computer, typing one letter at a time with limited mobility, writing down story after story about our Mennonite past and his childhood. These were the stories he wanted my brother and me and the grandkids to know, but stories he knew he wasn't going to be able to tell. And I imagined talking about how I couldn't ask for a better example of a lifelong partnership, watching my parents care and support each other as the disease progressed. My dad taught

me that when you find love in someone who is amazing and wonderful, someone who is better than you, all you can do is ask them to marry you and then spend every day after that trying to keep up.

But, my dad didn't die when I was in high school, or when I was in my 20's, or when I was getting married. He died now. And as I thought about what I wanted to talk about at the funeral, I realized that I had been using the wrong lens for all those years before. My mom tells a story about my dad: As the disease progressed, taking more and more away from him, she would have understandable moments of frustration and anger, asking "Why? Why did this have to happen to you?" My dad always responded the same way: "Why not me? Why should others get sick but I get to stay healthy?" I can't imagine that level of acceptance, especially for a doctor who knew what was heading his way. But that is how my dad lived his life. He wasn't one to ask what should have been or what could have been. He took life as it came to him and cherished life for what it offered. Recognizing his acceptance helped me recognize how I had been using the wrong lens. It hadn't been his struggle with Parkinson's that had taught me all those lessons. He was going to teach them to me regardless of any disease. He approached Parkinson's with perspective and resilience and a love of family because he lived life with perspective and resilience and a love of family.

I will always be grateful for how my dad accepted Parkinson's. He didn't let the disease change him and he didn't let it change what he was saying to me. It just changed how he was saying it. I love my dad and will miss him very much. ■

Grant delivered this eulogy at his father, Dr. Robert Wiens', memorial service on May 20, 2017.

NO GREATER GIFT

JOEL S. PERLMUTTER, MD, AND SUSAN DONOVAN, ADMINISTRATIVE ASSISTANT, WASHINGTON UNIVERSITY SCHOOL OF MEDICINE, MOVEMENT DISORDERS SECTION

The Movement Disorder Brain Bank is an extremely valuable research asset. We have made multiple discoveries regarding clinical manifestations of Parkinson disease and identified potential new targets for treatment. Some of the findings have been particularly surprising and were only possible with direct brain examinations, including identification of specific brain protein abnormalities that may contribute to thinking problems and deficits of specific chemical messengers in parts of the brain that provide rationale for new treatments. None of this work is possible without the generous help of those who donate their brain for our research studies.

Brain studies require substantial work and resources. The scarcest resource is brain tissue, so we want to make the best use of these studies. We learn the most when we can compare our findings from the brain studies to the individual's clinical manifestations of Parkinson's. Because of this, we learn most from those that participate in our long-term research studies at Washington University in St. Louis. Three of our faculty currently have NIH grants to support this work: Drs. Paul Kotzbauer, Meghan Campbell and Joel Perlmutter. Participants in these studies have provided permission for brain donation and have discussed this with their families to ensure a smooth procedure at a difficult time.

Grant funding helps defray the costs of brain examinations, which can exceed \$10,000 per brain. We also have support from the Greater St. Louis Chapter of the APDA to help with the costs for study participants from Illinois, which are substantially higher due to differing state laws between Missouri & Illinois. A new law in Illinois prevents us from bringing someone's body to St. Louis, so we have to send a technician to collect the brain in Illinois which significantly raises costs.

We also accept brains from people who have

not participated in a study, such as someone who was ineligible to participate in any other studies. However, we do not have funding to cover the additional expenses of retrieving a brain from someone who has died in Illinois but did not participate in a study. If an Illinois resident feels strongly about brain donation, they can still be a donor if family or others cover the costs of brain retrieval. Currently, this cost runs around \$750.

HERE ARE THE STEPS FOR BRAIN DONATION:

1. Tell your family that you want to do this so that everyone is on the same page at the time of death.
2. Complete a brain donation form. Obtain the form from Susan Donovan, 314.362.6026.
3. At the time of death, call our office immediately. That can be a direct call to Susan Donovan. If at night or on the weekend, call the exchange, 314.388.6138 and ask to speak to your Movement Disorder doctor.
4. If you have signed a consent form, the arrangement can be made quickly, with the phone call at the time of death.
5. If you have not signed a brain donation form, your family can still call the

exchange or our office during the day. We can obtain permission from the family over the phone.

The information we need at this phone call will include: time of death, cause of death (if known), address where the body is, phone number of next of kin and phone number where the body is. **Please note that we can only accept a brain donation from people who have been followed in the Movement Disorders Center at Washington University.**

Brain donation will not interfere with any planned funeral arrangements. If a person's family is planning an open-casket funeral, there will be no sign of the brain donation. Someone who also wishes to participate in the Washington University Body Donor program is able to do so; the Body Donor Program will coordinate with us. We will also share the results of the brain autopsy with families who are interested. A report takes approximately a year to be complete, sometimes a bit longer. When the report is complete, your physician will call and discuss it.

Brain donation is an amazing gift that moves forward our understanding of Parkinson disease. There is no greater gift. Together, we continue the fight against Parkinson disease. ■



Dr. Joel Perlmutter receiving a check for \$50,000 from Debbie Guyer as local supplemental funding for this fiscal year ending August 31, 2017. The \$50,000 will be used to analyze brain tissues and PET scans and extend the study of people with PD including clinical evaluations, cognitive testing, gait analysis, genotyping, lumbar puncture for spinal fluid analysis, MRI scans and postmortem brain examinations, from the APDA- Greater St. Louis Chapter. These grant monies (in addition to the \$30,000 granted in the fall) are only possible in addition to the annual grant of \$125,000 because of the efforts by the Greater St. Louis Chapter and our many readers who continue their support through tributes, fundraising events, and the year-end campaign. In addition, our Chapter has contributed \$20,000 to national research grants this fiscal year. We're proud to be contributing to the efforts to find causes and a cure for Parkinson disease.

DETERMINING WHAT TYPE OF CARE IS NEEDED

LEARN YOUR OPTIONS, EVALUATE YOUR RESOURCES, ASK THE RIGHT QUESTIONS

STACEY BARTON, MSW, LCSW, WASHINGTON UNIVERSITY SCHOOL OF MEDICINE

As a social worker, one of the most common requests I receive is for help getting additional care needs met. People often know there is help “out there” but really have no idea what type, how to access it or how it is paid for. At an APDA workshop archived on www.stlapda.org, I co-presented on this topic with Lori Zimmerman of ElderLink St. Louis. In this article, I will recap the presentation and provide you with the information needed on how to get help, what type to get, and how it will be funded.

IN-HOME CARE

The first place people often want to begin is looking at care they can receive that allows them to stay at home. Many people use the term “home health” generically, but it is important to realize that this term may not actually reflect the needs you have. I will use the term “home health” to refer to temporary health services in the home for an illness or injury, typically covered by medical insurance. I distinguish this from “private duty” which is not covered by medical insurance, does not require a skilled service (i.e., professional nurse, physical therapist, occupational therapist, etc.), and can continue for as long as you want this service.

Home Health is in-home care with a goal in mind. It is meant to treat an illness or injury in order to get better and regain independence. People receiving home health must be homebound; otherwise, they are expected to receive these services through outpatient clinics. Care is intermittent and temporary and is typically covered by Medicare Part A or Part B. Medicare Advantage Plans also provide this coverage but will have specific providers from which the recipient must choose. People with original Medicare pay none of the cost of home health care services and 20% of the cost of medical equipment (unless you have a supplement that will pick up these costs). There is no limit to the number of annual visits, but they will only continue until the person’s goals are met. A typical home visit is about an hour and

usually only lasts for a few weeks.

Home health requires a doctor’s order and the person receiving home health must be under a doctor’s care. The doctor must certify that s/he needs one or more of the following:

- Intermittent skilled nursing care (but not just blood draws), e.g., wound care, IV therapy, nutrition therapy, injections
- Rehab services: physical therapy, speech pathology, occupational therapy

The condition must be expected to improve in a reasonable, predictable period of time or require a skilled therapist to create or assist with a maintenance program. Once someone qualifies for nursing or therapy services, s/he may also qualify for social work services, intermittent home health aide, medical supplies and medical equipment.

Home health is NOT 24-hour care (or even extended hours of care), home delivered meals, homemaker, chore worker, custodial or personal care. This is where private duty comes in.

PRIVATE DUTY typically consists of personal care and homemaker services. It is not covered by medical insurance such as Medicare or commercial insurance. Some people may be able to receive a few hours of this care through Medicaid if they meet specific criteria, which include being impoverished and otherwise requiring nursing home care. These services may also be covered through VA benefits and are usually covered in long-term care insurance policies if the person meets the requirements of their policy. Private duty is rather expensive. Although there is a lot of variability, the average is about \$20 per hour through an agency, and many agencies require a four-hour minimum. People can save money by hiring someone privately, but there are caveats. In general, the advantages of hiring an agency are that they assume responsibility for screening, hiring

and firing staff, provide liability insurance, train the staff, and administer the taxes. In addition, you are assured that back-up staff are available if your primary caregiver is ill, on vacation or their car breaks down. They can also alter the staffing if the skill set required to care for the person changes. Finally, for individuals with long-term care coverage for private duty, you may be required to use a licensed agency for the care. There are some advantages of hiring a private aide outside of an agency. Primarily the benefit is cost. There may also be greater consistency with just one worker, you may have more choice in who provides the care, and there may be flexibility in scheduling such as not having a minimum number of hours.

ADULT DAY CARE

This is one of the most overlooked resources available. Adult Day Care (ADC) is a safe and therapeutic place for a person with a disability or dementia to go during the day to receive care, social engagement, and oversight. Most ADCs are open 10-12 hours per day, five days a week, and some offer regular or occasional Saturdays. Full and half-day options are available at most centers. The cost is quite reasonable, with an average about \$75 for a full day of care. The costs are covered through private pay, Medicaid, long-term care insurance, and VA benefits. Some ADC centers offer scholarships or a sliding scale payment option.

ADC provides a lot of care for the cost. Included in the care at most centers are meals, personal care, activities, and medication administration. Some centers also offer transportation, rehabilitation services, beauty salon, podiatry, and more.

RESIDENTIAL CARE

Sometimes remaining at home no longer becomes an option. There are several types of residential care, and many of these terms are used loosely and generically; when talking to providers, friends and medical professionals,

be sure to clarify that you are all talking about the same things.

First, don't overlook *independent living*. There are a number of campuses that provide housing for people who are older or disabled but independent. These are often apartment, villa, or cottage-like homes that include upkeep of the outside facilities and basic housekeeping. Many offer some meals, scheduled activities, and transportation. Additional services such as medication administration and personal care may be available but at the same cost as private duty care described above. Independent living is private pay and may include a refundable or partially refundable admission fee.

Assisted living is probably the term social workers hear used most loosely. For our purposes, we will consider assisted living (AL) facilities as well as residential care facilities (RCFs) together. In addition to RCF and AL, you may also hear the terms Supportive Living Community or Board and Care Home used in this category of care. There are slightly different licensing rules for AL and RCF, but in general these are facilities that provide protective oversight 24 hours a day, seven days a week, plus meals. Many, but not all, will provide medication administration. When looking at an AL/RCF, it is important to know what you are getting because of the variation in services provided. Additional services may be provided a la carte, and this can

add up quickly if you need a lot of care. Payment is typically private pay, although long term care insurance occasionally will cover this level of care and the VA may partially pay in some instances. For people with lower incomes, there may be access to a small state grant of \$292 per month, but this is only occasionally used because it often is not enough to bridge the cost gap. The average national cost of an assisted-living facility is around \$43,500 per year or about \$120 per day.

SNFs as facilities that provide 24-hour care also, but typically in a rehabilitation setting where people are recovering from an illness or injury and are attempting to maximize their potential so they can return home or return to a NH bed for ongoing custodial care. Many NHs offer SNF services in a wing of the facility.

People undergoing rehabilitation or nursing care in a SNF (pronounced "sniff") receive 24-hour care by a skilled nurse and/

managing this coverage. In general, SNF coverage is available to people who require skilled care beyond their hospitalization and have had at least three midnights in the hospital under inpatient status (this is key to know, as "observation" status doesn't count and people often don't know what status they are admitted under). If you are in the hospital, ask! People in a SNF no longer have to show continual improvement and rehab potential to stay under this care, but that doesn't mean that

Medicare will cover it for long. At best, Medicare covers the first 20 days of SNF care in full and then only a portion of 80 more days of care. If you have a Medicare supplement, then your portion is typically covered through the gap insurance. Bottom line: at most, SNF lasts for 100 days. However, the extensive regulations governing this level of care mean it is not a good planning tool for covering the cost of residential care.

Like SNF, NH care covers personal care, laundry, meals, medication administration, activities and all the basic needs of life, 24 hours per day, seven days a week. Care is meant to be personalized through a Care Plan, but the care is never one-on-one. Rehabilitation services are available, but, unlike SNF not included in the daily rate (they are usually billed to Medicare separately). For NH care, there are a number of payor sources including private pay, VA benefits, Medicaid (MO HealthNet) and

continued on page 8

ADDITIONAL RESOURCES

LONG TERM CARE FACILITIES, MISSOURI

<http://health.mo.gov/safety/showmelongtermcare/>

ADULT DAY CARE

<http://health.mo.gov/seniors/nursinghomes/adultdaycare.php>

FAMILY CAREGIVER ALLIANCE

<https://www.caregiver.org/>

MEDICARE AND HOME HEALTH CARE

<https://www.medicare.gov/what-medicare-covers/home-health-care/home-health-care-what-is-it-what-to-expect.html>

MEDICARE COMPARE:

Home Health

<http://www.medicare.gov/homehealthcompare/>

Nursing Home

<http://www.medicare.gov/nursinghomecompare/search.html>

VETERAN'S INFORMATION

<https://www.va.gov/GERIATRICS/Guide/LongTermCare/index.asp>

UNDERSTANDING LONG TERM CARE INSURANCE

<http://longtermcare.gov/the-basics/>

VOYCE (LONG TERM CARE OMBUDSMAN)

<http://www.voycestl.org/>

Nursing homes (NHs) and skilled nursing facilities (SNFs) are familiar to most of us, but there is often some confusion about what these consist of and how they are paid for. These are also terms often used interchangeably, but the services offered may differ between the two and some facilities offer "both" within their own building. For clarity, I will consider NHs as facilities that provide custodial care to people with significant care needs due to illness or age. I will define

or rehabilitation services. This care requires doctor's orders and is often covered by medical insurance such as Medicare. This is where the confusion often comes in. People know that Medicare covers SNF care and they mistakenly think this means that all NH care is paid for by insurance. This is not correct. Medicare will cover SNF care in very specific situations for a very limited period of time. As you might imagine, there are a lot of government regulations

GOLFERS SWING INTO ACTION FOR PARKINSON'S - TOURNAMENT BREAKS FUNDRAISING RECORD!



The APDA Golf Classic in Memory of Jack Buck was the ticket to have this spring! The tournament, held annually in May to support local Parkinson programming, services and research, was sold out by the end of March. Thank you!

We are deeply grateful to so many who enabled us to raise over \$176,000, a new record for this event. We will be able to help many people with Parkinson's, their families and care partners because of the generosity of those supporting this annual tournament.

The golfers enjoyed a wonderful day of great golf and picture-perfect weather. Dinner guests enjoyed a reception with hors d'oeuvres, a question-and-answer period with John Mozeliak, President of Baseball Operations for the St. Louis Cardinals, and Tom Ackerman, Sports Director KMOX radio, and a delicious dinner prepared by the Chef at Algonquin.

Some highlights of the evening included:

- Guest speaker Paul Hatz movingly describing the challenges that Parkinson disease presents for him and the love of his life, Carlyn, who was diagnosed several years ago.
- Dr. Mwiza Ushe sharing new treatment techniques he and other Movement Disorders Specialists are employing and progress made to enable

individuals with Parkinson's to live life to the fullest.

- An interesting and exceedingly successful auction, led by our returning and eminent emcee, Tom Ackerman.
- A thought-provoking conversation and glimpse into the mind of Cardinals John Mozeliak (Mo is credited with the new and much appreciated pace of play this year).
- Recognizing the efforts of our 2017 Golf Tournament Committee under the co-

and recognize their superb contributions to our community:

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LUNCH SPONSORS (\$2,500)-Barnes Jewish Hospital, Delta Dental

COCKTAIL RECEPTION SPONSORS (\$1,500)-For Pete's Sake & Budget Billboards, Ted Hume, Steve & Lynn Hurster, Matter Family Office, St. Louis Cardinals, Barry

leadership of Chris Vinyard and Rich Smith, and committee members Matt LaMartina, Alan Lemley, Barry Roufa, Dave Sadler and Matt Schumacher.

- Introducing Penny Westberry, Vice President of Chapter Development and Field Operations from our Home Office, enjoying her first visit to St. Louis and another successful fundraising event with the Greater St. Louis Chapter.

Our success is tied directly to the generosity of our sponsors, many who have continued to increase their support each year. We encourage you to offer your thanks when supporting their businesses

Roufa

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Helen Edwards, Mike Fink, Dennis Barnes, Sr.



Tom Ackerman, Debbie Guyer, John Mozeliak



Annemarie & Matt Schumacher

Jack Strosnider and TKC Holdings

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Blues, St. Louis Cardinals, Mark Yocum & Anheuser-Busch and Grants Farm. Special thanks to our returning hole-in-one sponsor, Autohaus BMW and banner and sign sponsor, FastSigns of Bridgeton.

CHARITABLE DONATIONS & GRANTS were received from Larry & Sonya Davis, Joe & Elissa Marchbein, Joel & Monica Perlmutter and Lundbeck.

VOLUNTEERS extraordinaire included Rebecca Farris, Mike Florent, Karl Guyer, Brian Hantsbarger, Ashley Kichura, Benjy & Joyce Levin, Jayme McKenna, Craig Miller, Matt Specter, Beth Templin and Amy Thomas. A special thank you to our Scottrade Volunteers for participating in the Day of Caring that Scottrade encourages their employees to engage in, for the community. ■

Bill Barrett for Town & Style Magazine AND Zach Dalin Photography

BE A CYCLESTAR AT THE CYCLEBAR



Saddle up and start pedaling to fight Parkinson disease! Join in The Cycle Challenge and raise funds to help people with Parkinson disease live life to the fullest.

The APDA Greater St. Louis Chapter and CycleBar are joining together on Sunday, October 1 from 3:00 to 5:00 pm to host THE CYCLE CHALLENGE. Caring individuals from 50 teams will ride for 50 minutes in a state-of-the-art indoor cycle studio. It will be an exciting outing, including a friendly competition to see who wins the ride. The ride will be followed by an ice cream social where the top fundraisers and ride finishers will receive prizes!

Funds raised by the Cycle Challenge will help support Parkinson-specific exercise programming in Missouri and Southern Illinois. Currently, over 500 individuals benefit from the Greater St. Louis Chapter's exercise programs each week. Exercise

is key to helping people with Parkinson disease manage their symptoms and slow disease progression. Research conducted at the Cleveland Clinic showed a 35% reduction in symptoms when people with PD rode a bicycle at a rapid cadence: 80-90 revolutions per minute. After the fundraiser, we hope to start a cycling for PD program in the bi-state region.

This is a great opportunity not only to raise funds but to see if cycling is a good exercise option for you. The research certainly supports it! There are only 50 bikes in the studio, so form your team soon to reserve your seat. We challenge each team to raise \$500 for a grand total of \$25,000 to support local exercise programs. Register and find more information at stlapda.org. ■



MIDWEST MINI-PARKINSON CONGRESS

On Friday, October 27, the Greater St. Louis Chapter of the APDA will present a Midwest Mini-Parkinson Congress in the bi-state region. Participants will choose from three tracks: Exercise, Care Partner Resources, and Treatment for Advancing Parkinson Disease. **Registration is required**, as space is limited. A box lunch will be provided. Invitations will be mailed out in September and will also be posted on our website at stlapda.org. Thanks to an educational grant from the JCA Charitable Foundation, we are able to offer the Congress at no cost to participants. At registration, each participant will select one of the following:

TREATMENT FOR ADVANCING PARKINSON DISEASE

Today's Parkinson disease (PD) drug development pipeline is rich with symptomatic therapies designed to address unmet needs. At this session, panels of Movement Disorder Specialists and individuals who have experienced symptomatic therapies will participate in a physician/lived experience panel to facilitate understanding of the procedures, indications and candidate selection. Panelists will share personal experiences and answer questions from the audience. Moderator will be Dr. Diego Torres-Russotto and Dr. Perlmutter will discuss medications such as:

- Inhaled levodopa and under-the-tongue apomorphine
- Extended release amantadine (for management of levodopa-induced dyskinesia)
- Deep brain stimulation (DBS) and Duopa (Dr. Mwiza Ushe & Dr. Paul Kotzbauer)
- Xadago and Rytary
- Nuplazid – a new treatment option for psychosis (Dr. Kevin Black)

EXERCISE AND PHYSICAL THERAPY

In the exercise track, best practices and specific exercise techniques will

be discussed by some of the renowned PTs in the area, Gammon Earhart and Ryan Duncan and special keynote speaker, Terry Ellis, PT, PhD, NCS, Director of the Center for Neurorehabilitation and the APDA National Rehabilitation Resource Center at Boston University. Fall prevention and freezing of gait will be of interest to all enrolled in this session as Dr. Pietro Mazzoni will include findings of his research. Individuals will learn about techniques that have been proven to improve quality of life and may slow the progression of this disease. This will be an interactive session, so wear your sneakers and be prepared to participate in selected exercises as you learn about dance, interval training, Rock Steady Boxing, Tai Chi, yoga and other evidence-based interventions.

CARE PARTNER RESOURCES

Caring for the care partner will be the third track. Continuum of care – topics such as in-home care, skilled nursing, assisted living and memory care will be discussed. Other topics will include:

- Protecting your assets as you navigate the healthcare system (elder law attorney)
- Monitoring the safety and judgment of your loved one
- Home modifications (Jamie Archer, MOT, OTR/L)
- ABCs of Medical Management (including update on the Medications on Time program)
- Dealing with dementia – managing changing personalities

Doors will open at 9:30 for check-in. Each track will meet from 10:00 to 2:00. The Congress will conclude with all participants gathering together for a final panel presentation. The Congress will take place at the United Hebrew Congregation at 13788 Conway Road in St. Louis. Please visit our website at stlapda.org to register and find more information. We look forward to seeing you there! ■

DETERMINING WHAT TYPE OF CARE IS NEEDED

continued from page 5

long term care insurance. NH costs are on the rise; the current national cost is about \$82,000 per year (about \$228 per day), and higher for a private room.

HOSPICE

Hospice care is included here since it can be a way to obtain additional care and should be considered when indicated. Hospice is intermittent care provided to people who are approaching the end of their life, defined as an expected prognosis

of six months. There are no crystal balls, so anyone in the late stages of PD might consider asking their doctor about hospice care. Hospice care can be provided wherever anyone lives – in the home or in residential settings. There are very specific admission criteria for hospice care, but once enrolled people typically receive several times per week, nursing and nurse aide visits, social work, chaplain support, and volunteer help. Many of your medications and equipment needs will be

paid for by the hospice. Hospice covers occasional respite and may cover continuous care in periods of crisis, but in general the home visits are about an hour in length, several days per week. In addition, there is 24-hour on-call support, and unscheduled visits can occur if there is a need. Medical insurance almost always covers the cost of hospice care in full. A person can go on/off hospice based on their medical condition.

We are fortunate in our area to have a lot of resources available for people who need additional help managing day-to-day life. By learning your options, evaluating your resources, and asking the right questions, you can utilize the right level of care at the right time which will improve quality of life for the individual with PD and their families and allow a person to remain as independent as possible for as long as possible. ■

FAMILY FUN AT INAUGURAL OPTIMISM WALK – PARTY WITH A PURPOSE!



It is Saturday, June 10, and there is wall-to-wall sunshine, blue skies and a wonderful breeze as we converge at Maryville University, just outside the Donius Center, honoring the memory of our members Connie & Walter Donius, and celebrating their son, Honorary Chair Bill Donius. Over 515 participants joined us to party with a purpose, starting with breakfast to rev the metabolism, sampling our exercise classes (Tango, Tai Chi, interval training) to warm up for the walk, joining

in family fun featuring a face painter and balloon twister, participating in a short walk around the designated course on campus, and concluding with a picnic under the The Gatesworth Communities *big tent*. Together we were able to raise over \$105,000 to support our mission of providing the support, education and research that will help everyone impacted by Parkinson disease live life to the fullest.

Our success was the result of the hundreds

of individuals, family members and friends who came to walk, generate funds, and recruit their family & friends to do the same! We want to recognize some of our top fundraisers: Tom Monahan, who raised \$1,580; Shirley Parisi, following closely with \$1,266; and Christine Klein, who brought in \$1,050. Christine's team, For Goodness Shake, also raised the most money per person, calculated by averaging funds raised by number of participants. Our top overall fundraiser, as well as our top team,

continued on page 12

OUR APPRECIATION GOES OUT TO:

CELEBRITY SPONSORS (\$10,000):

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DIAMOND SPONSORS (\$5,000):

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TEAMS:

Team Glenn - \$7,335
Team Tai Chi - \$5,535
Tricia's Exercise Classes - \$4,645
Team Stafford - \$3,775
Team Billy Sherbert - \$3,755
Rock Steady Boxing - STL
Crestwood - \$3,606
The Walkenbach's - \$3,590
Team Tremor (St. Peters Exercise Group)- \$2,845
Hope in Motion - \$2,255
Wash U Movers - \$1,876
For Goodness Shake - \$1,220

Team Papa - \$1,180
Team Cal - \$1,175
Team Wunderman - \$1,040
Beeb's Buddies - \$990
Tremble Clefs - \$885
Brennan Family Team - \$760
Specking/O'Toole/Pusateri/Kirn - \$595
Team Mary - \$580
Team Forsman - \$440
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The Gatesworth - \$340
Team Kreisler - \$300
Team Nancy Robb - \$297
Team Kimberly - STL - \$255
Team Gorman - \$220
Team Pew-Dehner Family - \$190
Team Liz Burns - \$140
Jim's Gems - \$130
Team Wiens - \$80
Team Cedarhurst - \$40
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Walking For A Cure - \$40

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FAMILY FUN AT INAUGURAL OPTIMISM WALK – PARTY WITH A PURPOSE!

CONTINUED FROM PAGE 9

was Team Glenn. Team Glenn has been our top fundraiser for the past three years, but this year they broke even their own record with a total of \$7,335 raised! Team Tai Chi also broke their previous record, raising \$5,535, and our third place team, Tricia's Exercise Classes, raised \$4,645. Congratulations to all of these wonderful *fundraising whisperers!*

We also want to extend our appreciation to our generous sponsors, starting with our **\$10,000 Title Sponsors,**

William A. Donius and The Gatesworth Communities (representing The Gatesworth, McKnight Place Assisted Living, McKnight Place Extended Care, and Parc Provence). Our **\$5,000 sponsors** included Carol House Furniture, The Delmar Gardens Families, James & Alison Bates Foundation; **\$2,000 sponsor** Garden View Care Centers; **\$1,250 sponsors** Bethesda Health Group, Jack Strosnider, In-Step Mobility; **\$500 sponsors**

Air Wheel, HousePT & Seniors Helping Seniors. We are also so grateful to our various In-Kind Sponsors including Maryville University and David Bruns, who provided us with the wonderful space in which to hold this event, Lunch Sponsor- Tom Jon's Catering, and Breakfast Sponsor- Dierbergs Markets.

Our gratitude is extended to all those who donated to, participated in and/or volunteered for the Optimism Walk. We especially wanted

to thank our large volunteer force who were everywhere making the walk easy to navigate, plus our committee members who did an amazing job planning/executing this successful inaugural event! Craig Miller, our distinguished Tai Chi instructor served as Emcee extraordinaire, and did a fabulous job of keeping the crowd informed and moving. We hope that you will all join us again next year for our 2018 Optimism Walk! We promise to make it an equally memorable

morning. Regretfully, we are unable to list all of our walk donors because of space constraints, but we invite you to view a complete list at <http://bit.ly/2uvzGCz>.

The photos captured at the event may be viewed on our website at www.stlapda.org; click on '2017 Optimism Walk Photos' on the right-hand side of the page and enjoy the activities all over again. ■



2ND ANNUAL SOUTHERN ILLINOIS GOLF TOURNAMENT DOESN'T DISAPPOINT

The second annual Southern Illinois Charity Golf Tournament was slotted to occur on May 20, but the weatherman would not cooperate. Fortunately, it didn't dampen spirits or the incredible support of the individuals and businesses in Southern Illinois who would not let the Parkinson community down. They conducted a very successful campaign to raise funds to "cure this debilitating disease and to support care partners and families who play such a vital role in the care of those living with Parkinson's."

A very successful raffle raised over \$3,300 and the remaining \$10,201.55 raised came from sponsors and charitable contributions from friends, family, neighbors and surrounding businesses. No one would rain on this parade! The committee comprised of Mike Meehan, Diane Gederman, and Courtney Landrum was motivated by personal connections and the untimely passing of Jack Meehan

and Bob Landrum. Considerations for 2018 will include a 3rd annual charity golf tournament or possibly a new 5K Walk/Run. Congratulations on a job well done!

SENIORS HOME CARE CELEBRATES 30 YEARS OF DELIVERING PERSONAL CARE AND SERVICE

In honor of Seniors Home Care, LLC's 30th anniversary in business, founder/owner Kit Whittington and her son Ryan Whittington, Managing Partner, asked businesses and clients to consider making a donation to the Greater St. Louis Chapter of the American Parkinson Disease Association, selected as their charity of support during this milestone year. Senior Home Care loves giving back to the community that has whole heartedly supported their agency over the past 30 years. They raised over \$700 for the Greater St. Louis APDA Chapter. We congratulate the Whittingtons for achieving this milestone and express our appreciation on behalf of the individuals and families they serve for the care they deliver and wish SHC abundant success in the next 30 years! ■



Missouri Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, www.stlapda.org, or call the APDA Information & Referral Center at 636.778.3377 or the facilitator at the number listed below.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	2:00 PM	Gayle Truesdell	636.923.2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street	4th Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2678
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	11:00 AM	Tricia Creel, DPT	678.951.3361
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard, PhD	636.778.3377
Columbia*	Boone	Broadway Christian Church 2601 W. Broadway	1st Thursday	4:00 PM	Patsy & David Dalton	573.356.6036 573.434.4569
Creve Coeur	St. Louis	Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl. CLI Rm. 415	3rd Tuesday	6:30 PM	Joe Vernon	314.614.0182
Creve Coeur	St. Louis	Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl., CLI Rm. 415	3rd Tuesday	6:30 PM	Doug Schroeder	314.985.7708
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Laura Sobba	636.931.7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314.869.5296
Jefferson City	Cole	Capital Region Medical Center Community Conference Room	3rd Friday	1:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Every Monday	3:00 PM	Nancy Dunaway	417.556.8760
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816.861.4700 x56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW Patty Waller	314.286.2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314.372.2369
Lake Ozark*	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy & David Dalton	573.356.6036 573.434.4569
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	573.201.7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314.846.5919
South City St. Louis*	St. Louis	Cure PSP Group - St. Louis Altenheim 5408 South Broadway St. Louis, MO 63111	4th Friday	11:00 AM	Beth Evans	314.732.3433
Springfield*	Greene	Parkinson's Caregivers Support Group Meyer Orthopedic and Rehabilitation Hospital 3535 S National Ave. Administrative Classroom	1st Wednesday	5:00 PM		417.269.3616
Springfield*	Greene	Parkinson's Young Onset Support Group Cox Medical Center 1423 N Jefferson Ave Meyer Center Conference Room C	4th Thursday	7:00 PM		417.269.3616

*denotes non-affiliated APDA support group

continued on next page



continued from previous page

Missouri Support Group Calendar

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Springfield*	Greene	Parkinson's Senior Support Group Cox Medical Center 1423 N Jefferson Ave Meyer Center Conference Room C	Last Wednesday	2:30 PM		417.269.3616
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Groomes, RN	636.926.3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573.543.2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283 660.485.6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314.713.4820
Webster Groves	St. Louis	Bethesda Orchard - Parlor Room 21 North Old Orchard Ave.	Last Friday	10:30 AM	Laurel Willis, MSG	314.471.6302
Webster Groves	St. Louis	Laclede Groves 723 S. Laclede Station Rd.	3rd Wednesday	3:00 PM	Shawn Riley, MSW	314.446.2452



Illinois Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, www.stlapda.org, or call the APDA Information & Referral Center at 636.778.3377 or the facilitator at the number listed below.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Alton	Madison	Senior Services Plus 2603 N. Rodgers Ave.	3rd Thursday	2:00 PM	Dustin Heiser	618.465.3298 x120
Belleville	St. Clair	Southwestern Illinois College Programs and Services for Older Persons 201 N. Church St.	2nd Monday	1:30 PM	Jodi Gardner, MSW, LCSW	618.234.4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, MD	618.549.7507
Carlinville	Macoupin	Carlinville Area Hospital Medical Office Building-Community Room 20613 N. Broad St.	3rd Wednesday - Schedule can fluctuate, please contact leader to verify date and time.	10:00 AM	Amy Murphy PT, DPT, NCS	217.854.3839
Centralia	Marion	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Betty Evans Helena Quaid	618.533.0224 618.493.6064
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Road	Every Monday	10:00 AM	Charles Rohn Chuck Arbuckle	217.549.6167 217.586.3100
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Mary DeLong Paula Beals	618.692.1346
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut-Meeting Room 2	1st Wednesday April-December	6:00 PM	Larry and Karen Ladd	217.377.4973
Mattoon	Coles	Odd Fellow-Rebekah Home 201 Lafayette Ave.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217.268.4428
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	3rd Sunday Odd num- bered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.483.4300
Quincy	Adams	Quincy Public Library 526 Jersey St.	1st or 2nd Saturday-Please contact leader	10:30 AM	Terri and Dave May	217.224.7027



Missouri and Illinois Exercise Classes

Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our funding comes from donations, so we encourage those who attend multiple classes to make a \$5 per week donation. This helps us defray the cost which run around \$10 per person. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our community. Our exercise classes meet once a week or otherwise as noted. No RSVPs are required. Check our website, www.stlapda.org, or call 636.778.3377 to find out any changes since publication.

MISSOURI

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Clayton	Fit 'n Fun The Center of Clayton, 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Chesterfield	Movement Training: Chair Side St. Luke's Desloge Outpatient Center, 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Ann Towey, PTA	314.205.6934
Chesterfield	Movement Training: Chair Side Friendship Village 15201 Olive Blvd., Friendship Hall-Door #5	Tuesday	1:30 PM	Travis Harper	314.223.9575
Chesterfield	Circuit/Interval Training 1415 Elbridge Payne, Ste. 163	Monday Tuesday	2:30 PM 10:00 AM	Tricia Creel, PT	636.778.3377
Chesterfield	Movement Training: Chair Side 1415 Elbridge Payne, Ste. 163	Monday	1:30-2:15 PM	Tricia Creel, PT	636.778.3377
Chesterfield	Tai Chi 1415 Elbridge Payne, Ste. 163	Wednesday Friday	Dynamic Standing 10:00 AM Chair Side 11:30 AM	Craig Miller	636.778.3377
Chesterfield	Yoga 1415 Elbridge Payne, Ste 163	Thursday	2:30 PM	Diane Davis	636.778.3377
Florissant	Movement Training: Chair Side Garden Villas North, 4505 Parker Rd.	Thursday	10:00 AM	Nancy Robb	314.869.5296
Kirkwood	Movement Training: Chair Side SSM Day Institute, 1001 S Kirkwood Rd.	Thursday	1:00 PM	Teresa Godfrey, PT	314.821.7554
O'Fallon	Movement Training: Chair Side Park Place at WingHaven, Independent Living Fitness Room, 2002 Boardwalk Place Dr	Wednesday	11:30 AM	Beth Templin, PT	636.778.3377
Richmond Heights	Parkinson's Performance THE HEIGHTS, 8001 Dale Ave.	Saturday	1:00 PM	Barry Nicholson	314.645.1476 (registration)
Richmond Heights	Tango Convergence Dance and Body Center, 7700 Clayton Rd., Ste. 120	Thursday	10:00 AM	Roxanne Maier	636.778.3377 (registration)
Ladue	Tremble Clefs Salem United Methodist, 1200 S. Lindbergh Blvd., Lower Level Choir Room	Saturday	1:30 PM	Linda McNair, MT-BC	636.778.3377 (registration)
South St. Louis County	Fit 'n Fun Garden Villas South, 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
South St. Louis County	Movement Training: Dynamic Standing Friendship Village Sunset Hills, 12563 Village Circle Drive	Friday	10:00 AM	Beth Templin, PT	636.778.3377
St. Peters	Movement Training Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle	Tuesday	Dynamic Standing 10:00 AM Chair Side 11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	Aquatics St. Charles YMCA 3900 Shady Springs Ln.	Thursday Summer Session July 3 - Sept. 8	1:45 PM	Alicia Bunn, CTRS	636.896.0999 x21 (Kathleen)
Town and Country	Tremble Clefs Maryville University, 650 Maryville University Dr. Walker Building-Community Room	Thursday	1:30 PM	Megan Moran, MT	636.778.3377 (registration)

ILLINOIS

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Carlinville, IL	Movement Training: Dynamic Standing Carlinville Area Hospital, Medical Office Building, Community Room, 20613 N. Broad	Thursday	10:00 AM	Amy Murphy, PT	217.854.3141 x377
Jacksonville, IL	Joy of Movement Spirit of Faith Church, 105 East Dunlap Street	Thursday	1:30 PM	Eve Fischberg, OT	217.494.4961
Quincy, IL	Be Well with Parkinson's Blessing Wellness Center, 4917 Oak Street	Wednesday	10:00 AM	Rita Arment, PT	217.223.8400 (registration, ask for Home Care)
Quincy, IL	BIG For Life Blessing Wellness Center, 4917 Oak Street	Monday	10:00 AM	Rita Arment, PT	217.223.8400 (registration, ask for Home Care)
Springfield, IL	Joy of Movement Laurel United Methodist Church, 631 South Grand Ave. West	Tuesday	1:30 PM	Eve Fischberg, OT	217.494.4961

Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list or if you'd rather receive an electronic version. Just call 636.778.3377 or email apdastlouis@apdaparkinson.org to let us know! Thank you in advance for helping us spend our resources wisely!

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
GREATER ST. LOUIS CHAPTER

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GOT INTERNET? – EXERCISE WITH US FROM HOME

WANT TO EXERCISE WITH A GROUP, BUT UNABLE TO MAKE IT TO ONE OF OUR CLASSES? WE HAVE GREAT NEWS FOR YOU! WE HAVE STARTED TO LIVE-STREAM SELECT EXERCISE CLASSES FROM OUR PARKINSON RESOURCE CENTER IN CHESTERFIELD, AND ALL YOU NEED TO PARTICIPATE IS AN INTERNET CONNECTION. TO JOIN IN, FOLLOW THE STEPS BELOW:

1. Visit www.stlapda.org/live
2. Scroll down to the gray box that says 'APDA Live Broadcast Entrance' and enter your name and email address. Be sure to click the box that says 'I agree to the site Terms & Conditions', then click the submit button.
3. Once you've logged in, simply click on the video that appears and join the class!

At this time, we are only live-streaming 5 classes/week. Our live streaming schedule is posted on the website. However, if you want to exercise but are not logging in when a class is currently streaming, you can still watch a pre-recorded exercise class. To watch an archived class, follow these instructions:

1. Visit www.stlapda.org/live
2. Click on the link to our YouTube Channel (in blue, directly beneath the exercise class schedule). You will then be redirected to YouTube.
3. Once on the YouTube Channel, you can scroll through the videos listed and click on whichever class you would like to participate in. A variety of classes are available, including seated exercise classes, interval training, yoga and tai chi.



EFFECTIVE AUGUST 1, PLEASE NOTE OUR NEW EMAIL ADDRESSES. OUR WEBSITE WILL SOON MOVE TO A LINK ON THE HOME OFFICE WEBSITE.

INFORMATION

apdastlouis@apdaparkinson.org

WEBSITE:

www.apdaparkinson.org/greaterstlouis

EMAIL:

Debbie Guyer, Executive Director

dguyer@apdaparkinson.org

Sarah Schmerber, Program Director

sschmerber@apdaparkinson.org

Tricia Creel, Wellness Coordinator

tcreel@apdaparkinson.org

Mike Garavalia, Campaign Manager

mgaravalia@apdaparkinson.org

Meredith Wallus, Office Coordinator

mwallus@apdaparkinson.org

SAVE THE DATES

AUGUST 19

Mark Twain Area Parkinson Support Group, 12th Annual Hull of a Race, at 8:00 a.m. in Hull, IL 5K/10K Competitive race, 5K Fun Walk, ½ Mile Kids' Fun Run

SEPTEMBER 30

University of Missouri Annual Parkinson Conference held in Columbia, MO, from 8:00 a.m. to 1:00 p.m. at the Holiday Inn Executive Center

OCTOBER 1

Cyclebar Challenge in Chesterfield, MO (see page 7 for more details)

OCTOBER 27

Midwest Mini-Parkinson Congress in St. Louis (see page 8 for more details)