PARKINSON'S

NOVEMBER 2018

Volume 32, Issue 4

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

Serving Missouri and Southern Illinois

IN THIS ISSUE

A Thanksgiving Wish1
Letter from the President 2
Exercise and Physical Activity: Keys to Living Well with Parkinson's 3
Pain and Parkinson Disease4-5
How Not To Die, Is In Fact, a Great Way To Live!6-7
Urinary Tract Infection (UTI) and Parkinson Disease 7
Tributes And Donations8-9
Young-Onset Mentor Program10
Should Ms. Daisy Be Driving &
How to Talk About the 'Hard Stuff'10 $$
DIY Optimism Events11
APDA Greater St. Louis News 12
Support Group Calendars13-14
Exercise Classes
Midwest Parkinson Congress16

AMERICAN PARKINSON DISEASE ASSOCIATION

Strength in optimism. Hope in progress.

1415 Elbridge Payne Road, Suite 150 Chesterfield, Missouri 63017

636.778.3377 www.apdaparkinson.org/greaterstlouis



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



Our Twitter feed at @APDAStLouis



And our Youtube channel at Youtube.com/
APDAGreaterStLouisChapter

OUR MISSION

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

AThanksgiving Wish



ew people are grateful to be diagnosed with Parkinson disease (PD), the symptoms it brings or the side effects of the medication. However, as we

approach Thanksgiving, it is important to take stock of what is good in your life.

It is important to take stock of what is good in your life.

Perhaps you've met some of the best friends you've ever had through

your support group. Maybe dance has helped improve your movement and Tai Chi your balance.

And, of course, there are the blessings of family and friends.

Here at the APDA-Greater St. Louis
Chapter, we are thankful to be able to
answer a question for a caller, or to
find the perfect support group for the
newly diagnosed person. We are happy
to send out a welcome packet to a new
"connection" or to schedule a one-onone PD101 session with an individual and
family members. We feel grateful for the
opportunity to provide quality education,
programs and supportive family services
to those living with PD every day. Mostly,
we are thankful for YOU and your support
throughout the year.

Thank you to those who fight and don't let this disease define them.

Thank you for advancing research through your donations or participation in clinical trials.

Thank you to those who provide care, who we sometimes forget to recognize in this family disease.

Thank you for your time which is precious.

Thank you for your financial support of our programs and services and for your involvement.

Thank you for creating awareness about Parkinson disease in the community.

Thank you for raising your voice.

Thank you for influencing change.

Thank you for inspiring us to do more.

This is a time for reflection and thanksgiving, but the words "thank you" cannot fully express how grateful we truly are. In addition to our words, please let our commitment to providing outstanding care and support, and our relentless quest to advance research serve as a sincere and wholehearted "thank you."

Here's to a holiday season full of blessings and love.

Warmly,



APDA GREATER ST. LOUIS CHAPTER

Deborah Dalin Guyer, MA

Executive Director
dguyer@apdaparkinson.org

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

Amanda Landsbaum, MS, OTR/L Wellness Program Coordinator alandsbaum@apdaparkinson.org

Melissa Skrivan, MBA
Director of Development
mskrivan@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.apdaparkinson.org/greaterstlouis

BOARD OF DIRECTORS OFFICERS

Dennis Barnes President Rebecca Farris Vice President Kathy Schroeder Secretary Brian Hantsbarger Treasurer

DIRECTORS

Christine Alsop Christine Eason Kevin Fairlie Erin Foster Gail Glenn Bryan Graiff Angie Lawing Joe Marchbein Caryn Mefford Matt Specter Paul Thakadiyil Jeff Waldman Grant Wiens

MEDICAL DIRECTOR

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 Betty Hayward Amanda Landsbaum Sarah Schmerber Meredith Wallus

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.

LETTER FROM THE PRESIDENT OF THE GREATER ST. LOUIS BOARD



Dear Friends,

have the privilege of serving as the next President of the APDA-Greater St. Louis Chapter Board of Directors, and I wanted to spend some time introducing myself to you, along with some of the great work that is happening right now at the APDA. My association with Parkinson's began when my father-in-law, Jim Mentel, was diagnosed with Parkinson disease. Since that time, I joined the APDA-Greater St. Louis Board of Directors

and was recently named President. Outside of my work as a board member for the APDA, I am the CEO of RGAx, the transformation engine of The Reinsurance Group of America (RGA). RGA is the only global reinsurance company to focus primarily on life- and health-related reinsurance solutions, and as such is a good fit for community partnerships. We were proud to have sponsored the recent Elliot & Mary Ann Stein Speaker Series featuring Dr. Michael Greger, who spoke about eating right to improve quality of life and longevity, our vision at RGA.

The fall is a great time to reflect on the accomplishments of the past year and begin to focus on goals for the year ahead. With that in mind I will begin by acknowledging Matt Schumacher for his leadership as President of the Board of Directors of the APDA-Greater St. Louis Chapter. As I enter into the beginning of my tenure as President, I can only hope to carry on Matt's legacy as an advocate for the organization. Under Matt and Debbie Guyer's direction, and with the support of our many Board members and volunteers, this year the APDA:

- » Hosted the first ever collaboration on a community-wide event, The Elliot & Mary Ann Stein Speaker Series, to raise awareness about good health and the APDA-Greater St. Louis Chapter.
- » Led the nation as the "model" chapter for the APDA, receiving the Milestone Award from the National APDA in recognition of reaching more than one million dollars in annual revenue towards achieving APDA's mission, the Salvatore A. Esposito, Sr. Award in recognition of the more than four million dollars contributed to APDA's research mission over the past 30 years, and our Executive Director, Debbie Guyer, was given recognition for her devotion, dedication and success in fulfilling APDA's mission since joining the Board in 1996, and serving as Information and Referral Coordinator, and later Chapter Executive Director since 2007.
- » Received the 2018 Award for Outstanding Community Partner by The Program in Occupational Therapy at Washington University School of Medicine in St. Louis.
- » Served over 18,000 people with personal or family connections to PD in the bi-state region & beyond.
- » **Generated over \$500,000 dollars for research and programs and services** through our Golf Classic in Memory of Jack Buck, Optimism Walk and Elliot & Mary Ann Stein Speaker Series.
- » Provided \$240,000 dollars in grants to the Advanced Center for Parkinson Research at Washington University for continued research in treatment and prevention of Parkinson's.
- » Welcomed our first Director of Development, Melissa Skrivan, who is responsible for engaging donors with the APDA mission and driving philanthropic support for research and programs.

As we approach 2019, we hope to offer additional programming, provide more funding for research, and drive even greater awareness of the resources available to those in need. It is with a personal passion for people with PD, and out of gratitude for the support the APDA-Greater St. Louis Chapter provided my family, that I take on the challenge and opportunity of leading our Board. It is an honor to serve in my father-in-law's memory.

Regards, Dennis

Exercise Keys to Living Well and Physical Activity: with Parkinson's

hen someone asks me what they can do to live well with Parkinson's, my number one recommendation is to keep moving. That may seem like a strange recommendation, since Parkinson's can make it challenging to move, but the evidence supporting the importance of physical activity and exercise is clear and undeniable. A study of over 2,000 people living with Parkinson's showed that those who were exercising for 150 minutes or more per week had better mobility, physical function and cognitive performance compared to those who were not exercising. The people who were exercising regularly also experienced less disease progression over the course of a year.

Exercise can convey a wide array of benefits, not the least of which is improved quality of life. Studies suggest that exercise can be helpful whether you have been living with Parkinson's for a day or for decades. It is never too early or too late to start, and there are lots of options in terms of types of exercises and activities that are beneficial. Aerobic exercise such as walking or biking - anything that gets your heart pumping harder and faster - can improve cardiovascular health and make movement more efficient. Balance exercises such as Tai Chi can help to improve postural stability and may even lead to a reduction in fall risk and number of falls. Stretching and flexibility exercises can help reduce stiffness. Strengthening exercises can improve the structure and function of muscles, making movement more effective. And complex activities that require learning of new skills, such as dancing, may help with physical function as well as cognitive function. Because there is not overwhelming evidence to suggest that one form of exercise is better than others, I recommend that people incorporate a variety of different types of exercises into their routines. After all, variety is the spice of life and can help to keep exercise interesting and enjoyable rather than doing the same thing day after day.

Speaking of day after day, we often underestimate the importance of our daily levels of physical activity. It is not just our planned or structured exercise that matters - our levels of activity throughout the course of daily life are also important. Being active, or spending less time sitting, is associated with less movement difficulty and a host of other health benefits. Ideally, we would all exercise for 150 minutes per week and get 10,000 steps per day, but in reality any amount of activity is better than being inactive. Do what you can to be active and set goals for yourself to keep moving.

If you are interested in learning more and receiving expert guidance regarding exercise and physical activity, you might

consider participating in our upcoming research study. As a participant in this study, you would receive comprehensive assessments and multiple visits with a physical therapist to develop an exercise and physical activity program tailored to your needs and help you set goals. You would also receive support to help you continue exercising for a 1-year period.



For more information, Contact the Washington University in St. Louis: Program in Physical Therapy at 314.286.1478

Please see our study advertisement for more information and give us a call, because exercise is one of the most powerful tools at your disposal to help you live well with Parkinson's.



Gammon M. Earhart, PT, PhD, Director, Program in Physical Therapy, Professor of Physical Therapy, Neuroscience and Neurology at Washington University



Pain and Parkinson Disease

Tricia Creel, PT, DPT, NCS, Wellness Program Coordinator, APDA-Greater St. Louis Chapter

While Parkinson disease (PD) is often characterized by the common motor symptoms of tremor, stiffness, slowness, difficulty with balance and shuffling gait, pain is actually a very common non-motor symptom. As with many non-motor symptoms, sometimes the onset of pain even precedes motor symptoms. One recent study found that 76% of people with Parkinson disease report some type of pain. The difficult thing is that pain may be caused by something other than Parkinson disease. People with PD can have the pain for many of the same reasons as the general population, but there are also aspects of pain that are unique to PD. Recognizing the type of pain and the source of the pain can be key to effective treatment.

TYPES OF PAIN

There are various classification systems for Parkinson disease pain, but the most frequently cited system includes five types organized according to their origin and treatment approach.

FORD'S PAIN CLASSIFICATION

Pain	Pain Classification
	Aching, cramping, muscle tenderness, arthritic changes, skeletal deformity, limited joint mobility, postural abnormalities
Musculoskeletal pain	May be exacerbated by rigidity, stiffness, and immobility, and relieved by mobility
	May fluctuate with dose of medication and improve with levodopa
Radicular/	Pain caused by a compression, inflammation or injury to a nerve root
neuropathic pain	Pain typically radiates along the course of the nerve
Dystonic pain (dystonia)	Associated with sustained twisting movements and postures; muscular contractions that are forceful and painful
	May fluctuate closely with medication dosing
	Originates in the brain, brainstem or spinal cord
Central or primary pain	Burning, tingling, "pins and needles" sensations, numbness, loss of touch sensation, often continuous
	Pain may vary with the medication cycles
Other pain	Headache, rectal, abdominal, oral and genital pain, akathisia (restlessness)

The most common type of pain experienced by people with Parkinson disease is musculoskeletal pain (41%), followed by other pain (31%), radicular pain (27%), central pain (22%) and dystonic pain (17%). People in the advanced stages of Parkinson disease are more likely to report pain and higher intensities of pain. Additionally, people who have pain tend to be more depressed and have poorer scores on quality-of-life measures. Not surprisingly, most depressive scores are reported by people who are in constant pain.

LOW BACK PAIN

One thing that distinguishes the pain experienced by people with Parkinson disease is the high prevalence of low back pain. One recent study found that 87% of people with PD experience low back pain compared with only 65% of the general population. Chronic low back pain (lasting longer than 3 months) is also more common with Parkinson's (48% of people with PD vs. 28% without). A study done in 2018 found that people at a higher risk for chronic low back pain are older, have higher levels of depression and anxiety, have more motor symptoms such as rigidity and have more impairments in their posture.

It can be challenging to tell whether low back pain is caused by the routine aches and pains of everyday living or by Parkinson disease. Regardless of the origin, all people with low back pain tend to be stiffer, have more difficulty making postural changes in preparation for moving, have more difficulty knowing where their limbs are during movement, have slower movements and have more difficulty maintaining their balance when perturbed. However, in the general population these impairments are typically localized to the trunk, whereas people with PD may experience them globally.

As a result, low back pain in Parkinson disease should be treated as more than just a musculoskeletal injury. Treatment should also address how the person moves. For example, someone with Parkinson disease may have changes in the way that they walk that impacts their lumbar spine. They may have altered mechanics with reaching, bending and lifting that can strain their lumbar spine. Addressing low back pain may also include treating depression and anxiety with medications, lifestyle changes and therapy or counseling. If rigidity is a contributing factor, complementary therapies like acupuncture or massage may help, although the benefits tend not to last.

DYSTONIC PAIN

Dystonia is characterized by painful, prolonged muscle contractions that can cause involuntary repetitive twisting, abnormal

LINK NOVEMBER 2018 VOLUME 32, ISSUE 4

movements and abnormal postures. People with
Parkinson disease often report painful cramping in their
arms, hands, neck or feet. Symptoms can improve with
Parkinson's medications, so it can be very helpful to track
how dystonic symptoms respond to the timing of the medication. In addition, botulinum toxin (Botox) injections may help.

A small amount is injected in overactive muscles, decreasing the rate of muscle firing for a few months. Physical therapy may be used in conjunction with medication. It is also worth considering complementary therapies such as yoga, Tai Chi and meditation, although there is not yet good research on these treatments as it relates to dystonia.

POSTURAL CHANGES

Parkinson's affects automatic activities, including automatic cues to stand up straight. As a result, people with PD may have rounded shoulders, a forward head or a backwards tilt of their pelvis, all of which puts strain on the spine and other joints. Stooped posture also makes it more difficult to reach overhead, resulting in altered reaching and lifting mechanics. Additionally, people with Parkinson disease can develop spinal disorders, including:

Scoliosis – lateral curvature of the spine

Anterocollis – dropped head

Camptocormia – bending forward when walking, sometimes as much as 90 degrees **Pisa syndrome** – involuntarily leaning to one side when sitting, standing or walking

A physical therapist can often be helpful in providing exercises, manual therapy and cues for stretching, strengthening and relaxing the appropriate muscles to improve posture. In some cases, surgical intervention is required.

ARTHRITIC PAIN

There is no evidence that Parkinson disease increases the risk for osteoarthritis (mechanical stress on a joint that causes breakdown of joint cartilage and underlying bone), but as age is a risk factor for both PD and osteoarthritis, it is not surprising that many people with PD also suffer from arthritis. Many of the movement and postural changes experienced by people with PD can exacerbate symptoms of arthritis. Additionally, arthritis in the spine is common and may contribute to spinal stenosis (narrowing of the spinal canal that can cause compression or injury to nerves as they exit the spine). There is strong evidence that exercise and joint protection techniques can decrease pain and disability from arthritis. Programs that include combinations of strength, flexibility, and aerobic exercises are more beneficial than general activity (e.g., cleaning the house). Even better are programs that include therapy and education about exercise to decrease fear of activity and improve adherence.

SUMMARY

Pain is a common symptom experienced by people with Parkinson disease, but it can be complicated to determine the origin of the pain. Understanding the different types of pain can help when you are communicating with your doctor. Because

treatment before starting a general exercise program.

Parkinson's medications are often a powerful tool to decrease Parkinson-related pain, it is important to track the timing of your medication with your symptoms. You also need to share with your doctor any other medications you take for pain – including over-the-counter drugs, herbs, vitamins and mineral supplements. Additionally, there is good evidence that physical therapy and exercise can help alleviate many types of Parkinson-related pain. To receive the most benefit, see a physical therapist for an individualized evaluation and



This is an open-label study of pimavanserin (Nuplazid) for patients with PD and depressive symptoms including fatigue, insomnia, low energy, etc. It's listed on the MJFF website at: https://foxtrialfinder.michaeljfox.org/trial/5224/

There is no placebo arm.
WUSM provides free
evaluation and drugs. The trial
lasts 8-10 weeks, and they will
pay for some transportation
costs. The study is looking for
people who either have not
been treated yet for these
symptoms or who are treated
but still have these symptoms.
This study is funded by
Acadia Pharmaceuticals.

For more information, please contact Kelly Streckfuss, RN, BSN, Research Nurse Coordinator, at the email or number listed below.

Kelly Streckfuss, RN, BSN, Research Nurse Coordinator I

₩ Washington University in St.Louis

Washington University School of Medicine, Center for Clinical Studies

Office: 314.747.3064

Kstreckfuss@wustl.edu



HOW NOT TO DIE, IS IN FACT, A GREAT WAY TO LIVE!

Debbie Guyer, Executive Director, APDA-Greater St. Louis Chapter

David Baugher, Jewish Light

he American Parkinson Disease Association-Greater St. Louis Chapter hosted Dr. Michael Greger for the inaugural Elliot and Mary Ann Stein Speaker Series. The event was only 134 hours long, but the health benefits will last a lot longer. Over 600 individuals were treated to an outstanding presentation by Dr. Greger at Congregation Shaare Emeth. One of the Presenting Sponsors, Jill Stein, described Dr. Greger this way: "Dr. Greger is such a character; he's just a delight to listen to and his knowledge is clearly encyclopedic." She goes on to say, "it is amazing the way he puts scientific material into readily comprehensible language and with such a sense of humor." We have received many emails and phone messages from guests who are now motivated to change their lifestyle and their eating habits, giving plantbased nutrition a try. This educational program reflected the mission of the American Parkinson Disease Association (APDA) to assist people with Parkinson's







From top: Michael Greger and Angie Lawing; Greger presenting at the Congregation Shaare Emeth; Dennis Guilliams, Susie and John Kinsella, Jill Stein

live a healthier life by living life to the fullest. Dr. Greger, an international public health speaker and *New York Times*, bestselling author, has dedicated his life to educating fellow physicians and consumers about the role diet may play in preventing, arresting and even reversing the leading causes of death and disability. He explains that "we actually have tremendous power over our own health, destiny and longevity" and "we must be ready to take personal responsibility for our own health and our family's."

The St. Louis Jewish Book Festival incorporated the Stein Speaker Series and Dr. Greger's presentation into their 2018 Festival, making it a Fall Bookend event for their Premier Pass holders prior to the Jewish Book Festival, which begins in November. This was the first time that the APDA teamed up with this annual literary showcase, which is among the largest of its kind in the United States. It gave the APDA-Greater St. Louis Chapter an opportunity to open our educational program to the community, drawing many guests who were not previously connected with the APDA. An APDA information booth was available during registration, and a pre-lecture slide deck provided additional information about Parkinson disease to the audience as they waited for the presentation to begin. There was considerable print and radio media coverage prior to the event that also helped raise awareness about the APDA in the larger community. >

We are grateful to our SPONSORS who made this event possible:

PRESENTING SPONSORS:

The Stein Family in memory of their parents, Elliot and Mary Ann Stein, and the James and Alison Bates Foundation, a Donor Advised Fund of The U.S. Charitable Gift Trust, honoring Nancy Rapp

SILVER SPONSOR: RGA

SPEAKER SPONSOR:

Linda and John Tracy

BRONZE SPONSORS: Terri and Gerry Brennan, Carol House Furniture, Centene Charitable Foundation, Clean Uniform Company, Myra and Gene Crandall, Emerson, Staenberg Family Foundation (a supporting Foundation of the Jewish Federation)

FRIENDS OF THE APDA: AbbVie, Ascension, Bethesda's Home and Community Services, Boston Scientific, Pultman Wealth Management Group, Steve and Lynn Hurster

HEALTHY LIVING SUPPORTERS: Commerce Bank, Karuna

IN-KIND DONORS: Caryn Dugan (STLveggirl) for the cooking demonstration and Chef Marianne Moore for preparing reception tasty hors d'oeuvres using recipes from Dr. Greger's cookbook, Edgewild Restaurant & Winery AND Lou Ann and Bob Nolan of Noboleis Winery for generously donating the wine selections for the reception, Fred & Ricky's and Frida's for their tasty preparations for the VIP Reception, Angie Lawing of Spoke Marketing for generously handling advertising and marketing, Amy Bornstein of the St. Louis Jewish Book Festival for their collaboration in making this event a Bookend for their annual Festival, and Lynda Wiens for the floral arrangements

STEIN SPEAKER SERIES COMMITTEE: Gail Glenn, Steve Hiler, Pam Lazaroff and Matt Specter and the SPICE BLEND GIFT PREPARERS: Pam Lazaroff, Chris Burgess, Steve Hiler, Nalini Mehta, Lynda Wiens

VOLUNTEERS AT REGISTRATION AND THE PRE-EVENT RECEPTION:

Laura Argyres, Jay Bender, Denny Bernstein, Jamie Brill, Ronnie Brockman, Paul Chasteen, Marina Clements, Ed & Linda Dahl, Rich Distler, Brittany Frazier, Barbara Furman, Mitch Furman, Gail Glenn, Ann Groomes, Karl Guyer, Jody Holborow, Sarah Kalishman, Michelle Kezele, Heidi Knuckles, Benjy & Joyce Levin, Monica Lynde, Tricia Niehoff, Jody Reynolds, Sherrie Rieves, Nancy Robb, Libby Ross, Celeste Schmeiderer, Erin Schreiber, Doug & Kathy Schroeder, Makenzie Skrabal, Matt & Ashley Specter, Helen Stolar, Maddy Urban, Ken Wagner, and Lynda Wiens

LINK NOVEMBER 2018 VOLUME 32, ISSUE 4

Urinary Tract Infection (UTI) and Parkinson Disease

Johanna Hartlein, RN, MSN, FNP Nurse Practitioner, Department of Neurology, Washington University Movement Disorders Section

Although most people are familiar with the motor symptoms of Parkinson disease (PD), such as tremor or muscle stiffness, non-motor symptoms are often more prevalent and can be the most troublesome. Urinary symptoms such as increased sense of urgency, frequency, nocturia (frequent urination at night) and incontinence are very common in people with Parkinson's and can significantly impact an individual's quality of life. Urinary Tract Infections (UTIs) are actually the most common infection that is associated with worsened motor or cognitive symptoms in PD. If left untreated, UTIs can result in hospitalization and can even lead to serious infections in the blood or to death.

UTIs are very common in people with PD for several reasons. First, Parkinson disease itself causes changes in your bladder function. A majority of people with Parkinson's have residual urine left in their bladders after urinating, which can lead to infections. Motor symptoms like tremor, rigidity and decreased dexterity can also make it more difficult to wipe and maintain hygiene. In other words, both PD itself and its symptoms can predispose individuals to urinary tract infections.

If you are concerned that you or your loved one may have a UTI, common symptoms to look for include pain with urination, changes in urine color or odor, inability to start flow, increased incontinence and fever. While it is true that UTIs may cause all of the above symptoms, they do not always cause those symptoms in people with PD. Sometimes, people with Parkinson's may experience a "silent UTI" meaning that they have no urinary symptoms at all, but instead have worsened cognitive or motor symptoms. For example, family members will call their doctor to report that their loved one has had a sudden increase in falling,

confusion, development of hallucinations (seeing things that are not there) or suspicious thinking. While a UTI cannot explain an increase in movement or thinking difficulties in every case, it is reasonable to collect a urine sample to check for an infection. If a urinary tract infection is present, many times people will return to their typical level of thinking and mobility after receiving treatment.

It is important to consult with your doctor about the best medications to treat urinary symptoms, particularly if you or your loved one has cognitive symptoms or hallucinations. Some medications for overactive bladder can cause an increase in confusion or hallucinations. Other medications for starting urinary flow or to help with bladder emptying can cause a drop in blood pressure, so these drugs should be used cautiously for people with orthostatic hypotension (sudden drops in blood pressure when standing). Lastly, sometimes people with PD can have a "colonized" bladder. This means that no matter how much antibiotic you take, the bacteria is always going to be present. It essentially lives there now and cannot be eradicated. However, in people with colonized bladders, antibiotics are still used if the patient has urinary symptoms of a UTI (vs. cognitive or motor worsening). If you are concerned about bladder and urinary symptoms, your treatment team may refer you to your primary care physician or a urologist, a specialist in bladder problems. Let your urologist know that you have Parkinson disease and discuss any medication or treatment concerns with them. Inform your healthcare team and Parkinson specialist of any new treatments, especially new medications, as they may affect your PD symptoms.

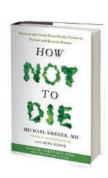
Continued from previous page ▶

Dr. Greger recommends a "Daily Dozen" checklist of foods to help stave off disease. "I think if there were three things to add to one's diet, it would be berries, greens and beans," he said. "If there were just three things to remove from one's diet, it would be trans fats - those partially hydrogenated oils, processed meat and soda." Dr. Greger was inspired to write his book, How Not to Die, from the experiences of his grandmother, who was confined to a wheelchair at age 65 and received a "medical death sentence" from endstage heart disease. Thanks to dietary changes and exercise, she went on to live for 31 more years and since then, Dr. Greger has made it his mission to educate people about nutrition.

Dr. Greger said that it is important to understand that many foods aren't objectively bad or good but have to be seen as part of a continuum. "Are eggs good? Well, compared to the breakfast sausage next to them, yes," he said. "Compared to oatmeal? Not even close. That's how you have to think about food." Regardless, he said, making good choices has a simple logic, what economists refer to as an opportunity cost. "Food is a zero-sum game. Every time we put something in our mouth, it is a lost opportunity to put something even healthier in our mouth."

Following his presentation, Dr. Greger took questions from the audience. Charlie Brennan, host of "The Charlie Brennan Show" on KMOX Radio, moderated the Q & A portion of this program. Further questions may be submitted to Dr. Greger through his **nutritionfacts.org** website.

There are How Not to Die books available at the APDA Resource Center in Chesterfield, should you be interested in purchasing one. Call 636.778.3377 to reserve your copy.



Tributes & Donations

07.01.2018 to 09.30.2018

Donations of \$25 or more are listed in the tribute pages. Every donation in any amount is greatly appreciated.

IN CELEBRATION OF

Austen Douglas Carlie's Birth

Debbie Guver

Bob Cohen's 75th Birthday Terri & Bill Taylor

Rilla Fisher-Pugh's 75th Birthday

Bernice Brandmeyer Shirley & Richard Busse Debbie Guver Mr. & Mrs. Gene Hutchins Ree & Jim Lang

Larry Freyman's 70th Birthday

Donna & Steve Broderson Julie & Jeffrey Lazaroff

Lisi Furman & Jason **Berger's Engagement**

Alan, Laurie & Aliza Dien Yaillen

Bill Gerth III's Birthday Erika & Bill Gerth, Jr.

Tricia Goldman's Birthday

Gail & Larry Glenn

Debbie Guyer's 65th **Birthday**

Terry Friedman Joe Marchbein Alan, Laurie & Aliza Dien **Vaillen**

The Birth of Pam & Neil Lazaroff's Grandchild

Ellen & Norm Farber

Neil Lazaroff's Birthday

Ellen & Norm Farber Debbie Guyer

Pam Lazaroff's 70th **Birthday**

Madeleine & Harvey Elkins Ellen & Norm Farber Debbie Guyer

Barb Lindhorst's 75th Birthday

Jack Strosnider

Debbie Guver

Andrea Lindner's Birthday Debbie Guyer

Lou Ann & Bob **Nolan's Anniversary**

Susan & Denny O'Leary's **50th Wedding Anniversary** Mary Lee & Paul Gund

Phyllis Ross' Birthday **Anthony Berens**

William Russell's Birthday

Marilyn Scott

Eileen & Larry Schechter's Birthdays

Terri & Bill Taylor

IN HONOR OF

Jacqueline Aldridge Marvin Aldridge

Roger J. Decker

Brenda & David Andrews

Barbara Furman's Speedy Recovery

Alan, Laurie & Aliza Dien Vaillan

Molly George

Ann & Randy Lipton

Debbie Guver

Dot Rasmussen

Nancy Klein

Bill Black Judy & Pat Klein

Gloria Lash

Jeff Lash

Martha Monahan

Shannon McCarthy, **Shamrock Interiors**

Judi Nassif

Denise & Dave Loseman

Joel Perlmutter's **Speedy Recovery**

Debbie Guyer

Doug Schroeder

Peggy & Mark Holly

IN APPRECIATION OF

Dennis Barnes

YPO St. Louis Chapter

Tricia Creel & APDA Staff

Bill Sorrell

Bill Donius

St. Louis Bank

Kevin Fairlie

Fitch & Associates

Kevin Haller

Central Missouri **CPCU Society**

The Staff of St. Louis APDA

Mayer Levy

IN MEMORY OF

Jim Braatz

Karen Braatz

Anna Branson

Jean Griffard

William Bruchhauser Kay Bruchhauser

Nola Bea Campbell

Donna & Marion Phipps

Donna Rowling Williams

Teresa Claves

Elizabeth Ashlev

James Cloninger

Nancy & Steve Strohbeck Merry & Craig Thierry

Thomas Cole

Sharon Book Cindy & Bryan Donnelly The Ferguson Family James Gerst Healing Touch St. Louis Cathy & Don Marek Catherine & Tim Pennington Esther & Bill Plowman Karen & Daniel Schlegel Julie Stackhouse

Gerald Commens

Peter Torres

Laurie Watt

ANSYS

Barbara Van de Riet Paul Van de Riet

Betty Coppedge

Nancy Goodson

Earl Crites

Catherine & Earl Adkison Mr. & Mrs. Richard Crites

Clara Cytron

Gail & Larry Glenn

Margaret Daues

Teresa & Francis Schwartze

Jay Bender Terri Hosto Jolene & Marvin Skoglund

Frederick Femmer

Jana Wade

Adam Gallo

Barbara Gallo

Norman Giovanni

Ione Buelt

Lynn Goren

Marc Kaufmann

Stephen Hale

Cathy & Earl Adkison Terri Choate Diane & Don Donlon Kathy & Richard Easley Jo Ann & Terry Gravemann Darlene & Larry Hale Fred Judkins Lois & Jasper Kermans Julie & Edward Manton Kay & JD Medlock Joyce Miller Norma & Dale Plank St. Peters Exercise Class **Sunday School Class**

Leo Hawkins

Pamela Hawkins

Charles Hendershot

Judith & Oral Wilson

Carol & Lyle Hull & Family

Mary Hughes Charles Hughes

Florence Jacques

Rochelle Sherman

Dr. Frank Johnson

Lynda Wiens

Donna Rae Judkins Cathy & Earl Adkison

Donna & Steve Biermann Carmen & Charles Bracken

Roberta & Bob Burk Sal DiFranco

Diane & Don Donlon

Sherry Downen

Connie Hale

Hock Mechanical, Inc.

Patricia & Philip Kapfer

Lois & Jasper Kermans

Karin & Brian Langhauser

Joanne & Ronald Naumer

Rebecca & Kyle Orf Dale & Norma Plank

Ann & Robert Schulte

Carl Specking

St. Peters Exercise Class Carol & John Tiefenbrunn

Elaine Kramer Gail & Larry Glenn

Brian LeDoux

Carol & Bob Weber Ronnie Loftus

Jan & Tom Cowan Joanne & Mike Loftus

LINK NOVEMBER 2018 VOLUME 32, ISSUE 4

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

Sherry Lowe

Cathy & Earl Adkison Nancy Cook Sue Cook-Allen Betty & Jere Guy Debbie Heikkila Lisa Ishell Marcelline & Wade Schott Leslie & Don Vaughan

Eileen Manes

Shirley Amerine

Patsy Mayer

Rosita Calazanz The Calasanz Family Michael Cardenas Dave's Friends at the SAGA Comic Book Club Mary Lippold Krista Sheriff **Bill Thompson** & Patty Biscotti

Don McGuire Jean Griffard

Carolyn McKie

Janice Asher Cathy Grace

Merle "Butch" **Mehrtens**

Nadine & Donald Gericke Allison & Douglas Ludwig Dorothy & Charles Myers Shirley & Leroy Trost Gladys Wittenauer-Thiele

James Mentel

YPO St. Louis Chapter

Wilson S. Miller, III

Judy & Warren Livingston **Emily McKeown** Barbara Sussenbach

George Montigne

Eva Sketoe

Les Muckerman Linda Amundsen Ann Beatty Pat & Roman Beuc Jessie & William Cleary Mary Devine Sue & Mike Dolan Mary Early Linda & Roger Heape Jim Heinen Ann Lena Linda McDonald

Jill & Bob McKendry

Kathy & Marty O'Brien Kathleen Palumbo Nancy Romano TKO Evolution Apparel Carolyn & David Zwart

Ronald Naumer

Diane & Don Donlon Connie Hale Helen Jackson Lois & Jasper Kermans Deborah & Wayne Nathanson Norma & Dale Plank St. Peters Exercise Class

Rosalind Neuman Gail & Larry Glenn

Rev. George Nicozisin Sylvia Nicozisin

Kathleen Paluczak

Mary Ann Druhe Dorothy & Chauncey Finch Kelly & Patrick Fischer Eileen & Conrad Haubrich Wendy & Norman Ruud Tom Schmitz Sharon & Jim Wiseman

John Patton

Linda Pauly

Edna Posey

Advanced Labeling Systems & General Credit Forms Patty & Todd Baucom **Brothers & Sisters** of USF Holland Cynthia & Robert Burgess Bonnie & Jack David Suzanne & Roy Evans Roberta & Robert Foland Kim & John Fox Paula Gunn Stephan Gunn Donna & Archie Lees **Donald Posey** Jan & Jack Yacovelli

Robert Prichard

Jean Prichard

Henry Rauh

Amanda Montgomery

James Roselli

Janet Mattea

Boyd Schmidt Kay Anstine

Steven Schulte

Tom Henderson Mr. & Mrs. Scott Marks **Wendy Mathis** Carol May Dee More Judy & John Pohl **Prince Minerals** Steven Schmitt Laura Waisner

Stanley Shmuger

Anne & Chris Brown

Sue Showalter

Mary Gosney Shirley Wadleigh Katherine & Charles Wilson

Marty Shrader

Jean Cody

Ely Shrauner

Barbara Shrauner

Carolyn Lee Stockton

Sarah & Ben Burkemper Terri & John Doerr Loretta Grbac **Debbie Guyer Evelyn Matt** Michelle & John Munn Jeannette Santagato The Staff at KOC Lvnda Wiens

JoAnn Sturm

Kathie & Bruce Burkhardt

Shaw Weiner

Lisa Day

Marian Whitehead

Ann & Robert Schulte

Dick Whiteside, Jr.

Myrna & Winston Bailey Karen & Larry Buck Patti & LeRoy Gladney Gayle & Jim Powers Brenda & David Ross

& Family Lori & Eddie Ross & Family Nan & Mike Scarry **Donna Schimmel** Carla & Joe Talbot Mary Lou & **Donald Thompson**

Karen & Robert Turnbull

Gene Wittman

Nancy & Mike Klein Lori White

GENERAL GIFTS

Up to \$99 Martha Atkins Mira Bantcheva **Bill Billings** Lewis Billingsley **Karen Castanis** Linda & Michael Cerutti Kathy & Garry Chaput Nancy & Dick Chin James Cottrell lim Crates Mary & Ray DeVasto Rich Distler Ernestine Edelmann Larry Gassei Linda Gibbons Mary Ann & Jerry Gunn Carol & Arnold Henke Erica & David Hood **Edith Kapfensteiner** Lisa Knoll Cherng & Kou Li Linda Liepmann Terry McDonough Donna Nickum

Janet & Kenneth Munger Lou Ann & Robert Nolan Sandra Parker Peter Pisaneschi **Judy Pouyer** Asma & Khalid Qayum **Richard Rawlings** Jeff Rose

Judith Schuster Patricia Sheehan Rita Sidall **Rodney Stecher** John Strebler Marilyn Strothman Mary & Michael Sullivan Carmella Swan Judy & Paul Taxma Renee Tedesco Murlene Thayer

Marie & Stanley Williams

Vivian Zvibleman \$100-\$499

Georgia Wright

Robert Babione Linda Bouchard Barbara & Al Buck Chris & Ralph Burgess Cecile & Jerry Davis Susan & Norb Doll Julie Dubman Leah Forst

Nancy & Tom Freeman Cathy & Dennis Frey Nancy Gerber Robert Green Kathleen Holas Linda & Steve Kilgore Nancy & Mike Klein Freda Lohr Ann & Larry Mauch Jeanne & Phil McDermott Karen & Jim Miller Alice & Andre Nutis Norma & Dale Plank Joseph Price Diane & Karl Schoenefeld Rev. Eugene Selzer Cindy & David Smalley Bill Sorrell Anne Marie & Todd Tobiasz Terry Toolen **Robert Wargel**

\$500-\$1,999

Sarah & David Butler Phyllis & John Evans Penny Kodner Annetta McAninch Martha Monaghan Shirley & Robert Waggoner

Dr. & Mrs. David Watkins

\$5,000+

Carole & Chuck Borchelt

ANNUAL GIVING

\$500-\$1,999

Aurelia Konrad Charitable Foundation Rotonda Foundation

Young-Onset Mentor Program

Are you under the age of 50 and have been diagnosed with Parkinson Disease within the last 2 years? If so, you may be eligible to participate in a new mentorship program where people who are newly diagnosed are paired with someone who has personal experience living with young-onset Parkinson's. The trained mentor will be available for a year to provide resources and support.

For additional information or to sign up, contact Amanda Landsbaum, OT, Wellness Program Coordinator, APDA-Greater St. Louis Chapter, at 636.778.3377 or alandsbaum@apdaparkinson.org.





SHOULD MS. DAISY **BE DRIVING**

& HOW TO TALK **ABOUT THE** 'HARD STUFF'



he ability to drive can have a big impact on independence, participation in activities and sense of self-worth as a productive member of society. When someone has been driving safely for many years, it can be very hard to determine when to retire the keys. We were delighted to have Sylvia Nissenboim, LCSW, and David Carr, MD, speak on this topic at our Parkinson Education Program (PEP), held at Congregation Shaare Emeth in August. Sylvia spoke about practical ways to have hard conversations with family members. Some of the tips that she provided were to slow down and become curious, to validate what the other person is feeling and to reach out for help if needed. Dr. Carr reviewed the data around safety of older drivers and talked about the current tools used to assess fitness to drive. Both speakers provided a wealth of information to the over 300 people in attendance. We were also grateful to hear from John Brisco, a person living with Parkinson disease who has retired from driving. He reassured the audience that it is very possible to stay independent and engaged using public transportation. Thank you to all three of our amazing speakers!

Based on feedback from families on this topic, the APDA-Greater St. Louis Chapter is working with Dr. Carr to develop a workshop where families will create a specific plan for driving retirement. The workshop will cover understanding how symptoms can affect driving, researching local transportation options, learning more about driving assessment tools and creating an individualized retirement plan. We hope this will help decrease the stress that often comes with a decision to stop driving and will reduce the chance that someone continues driving past the point when they are no longer safe. This workshop is planned for the spring of 2019. If you are interested in pre-registering or have guestions, please contact Tricia Creel, Wellness Program Coordinator, at

tcreel@apdaparkinson.org or 636.778.3377.

If you missed the PEP meeting, it is archived on our website at www.apdaparkinson.org/ greaterstlouis.

Please contact us at 636.778.3377 if you would like information about local transportation resources or driving assessment programs.



We received a lovely letter from 9-year-old Ellen Rozmaryn following the passing of her grandfather. Here are some excerpts about her experience raising funds for the APDA-

"On November 30, 2017, my grandfather, Phillip John Hampel, passed away in a nursing home. There were many causes of his death, but the main cause was Parkinson disease. I remembered how I always hated seeing my grandpa sitting helplessly in a wheelchair. Then I thought about all the other people in the world that had to see their family members also in a wheelchair. I had an urge to do something.

My mom told me about the neighborhood garage sale. I was up all night thinking of all the wonderful things I could do. I would make little crafts and sell them at a separate little stand. I would also make a fleece quilt to raffle off. I imagined my grandmother's happy face when I told her how much money I had earned. My siblings and I all wore the Parkinson's t-shirts that our grandma got at a Parkinson's program. When we counted our earnings at the end of the day, we'd collected \$200. I want to donate this money to help find a cure for Parkinson disease in honor of Phillip John Hampel, my beloved grandfather."

Thank you, Ellen. I am certain that your grandparents are so very proud of your efforts, just as we are!

Mah Jongg and Bridge

On Wednesday, August 22 at the Richmond
Heights Community Center, 48 Mah Jongg and Bridge
Players paid to play to raise funds for the APDA-Greater
St. Louis Chapter. One of our constituents, Margie Silverblatt,
organized this sell-out event with the support of
Phyllis Siegel. The foursomes registered
and joined in the games, lunch and raffles
raising \$1,100 to benefit the APDA-Greater
St. Louis Chapter. Way to go, Margie!

Fundraising Events

Hull of a Race

Lucky 13 – the 13th annual Hull of a Race took place on August 18 in Hull, IL, raising funds for the APDA-Greater St. Louis Chapter. The day consisted of a professionally timed, competitive 10K race held on a certified course, a 5K fun walk/roll, and a ½ mile kid's fun run with trophies, medallions and ribbons awarded. Results this year set a new record, with \$11,000 raised to fund Parkinson's research. Hull of a Race has raised a total of \$97,500 since 2008. Congratulations and heartfelt thanks go out to Marilyn White and the Hull, IL, community who support this event every August. Save the date of August 17, 2019, in Hull, IL, for lacing up your tennis shoes to help Hull of a Race surpass \$100,000 raised to fund Parkinson research.

\$1,590 Tractor Cruise

The 11th Annual Knights of Columbus – "Journey for Charity" – Tractor Cruise rolled through a 30-mile route, passing St. Clair, Union and ending in Washington, MO, on Sunday, September 9. The Tractor Cruise concluded with a BBQ and Tractor Show in Washington, home of our constituent and annual Tractor Cruiser, Bob Weber. Bob raised another \$1,590 in this year's Journey for Charity and donated all funds he personally raised to the APDA-Greater St. Louis Chapter. This is the fourth Tractor Cruise Bob has participated in since 2014, raising over \$4,571 to support our mission. In addition to the Tractor Cruise, Carol and Bob facilitate a very active Parkinson's support group held monthly in Washington. We are most grateful for their involvement in this annual event and for their leadership with the support group and Parkinson community.

\$11,000

APDA-St. Louis NEWS

Welcome to Our New Board Members

Brvan Graiff. CPA/ABV/CGMA is the Partner in Charge of the Brown Smith Wallace Transaction Advisory and Litigation Support group. He has more than 25 years of diverse financial and operational experience in public and private companies. Bryan's father, Dr. Ron Graiff passed away this year, after an 18 year battle with Parkinson's. Bryan was interested in serving on the board to help find a cure for Parkinson disease. With his background in reorganizations, acquisitions and restructurings and board experience, Bryan brings valuable expertise and knowledge to our 2018-2019 Board of Directors.

Paul Thakadiyil is the Executive Director of Business Operation Solutions at RGA and comes with an interest in helping people. Reinsurance Group of America is in the business of health and insurance. Paul has an extensive background in IT and constituent relationship management and will add much value to our operations.

Grant Wiens is an attorney and Partner at Mickes O'Toole. Grant's father. Dr. Robert Wiens, had Parkinson Disease. Grant's mother, Lynda Wiens is an exceptional volunteer with APDA-Greater St. Louis Chapter, co-leading the Care Partner Only Support Group, and assisting with our educational programs and fundraising events. Grant and his family have been active participants in our events since relocating back to St. Louis and we're delighted he could join the Board.



APDA Greater St. Louis Chapter is proud to welcome **Melissa Skrivan** as the organization's Director of Development. In this new role, Melissa will be responsible for engaging donors with the APDA mission and driving philanthropic support for research and programs. She joins the APDA-Greater St. Louis Chapter team from The Foundation for Barnes-Jewish Hospital, a non-profit organization that raises funds for Barnes-Jewish Hospital, Barnes-Jewish West County Hospital, Siteman Cancer Center, Goldfarb School of Nursing, BJC Home Care and Hospice, Evelyn's House, and Washington University School of Medicine. During her more than nine year career in non-profit fundraising, Melissa has helped build organizations, increasing their community involvement and reach.

Welcome, Melissa!





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

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Ballwin	St. Louis	Meramec Bluffs Care Center 1 Meramec , Veterans Rm.	4th Tuesday	2:30 PM	Chaplain Chris Nilges	636.923.2338
Cape Girardeau	Cape Gi- rardeau	Cape Girardeau Public Library 711 N Clark Street	4th Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2678
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	11:00 AM	Tricia Creel, PT	636.778.3377
Chesterfield 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
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
De Soto	Jefferson	StoneBridge – The Villas 1550 Villas Drive	Last Wednesday	3:00 PM	Jennie Lessor	636.586.6559
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Laura Sobba	636.931.7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314.869.5296
Jefferson City	Cole	Capital Region Medical Center Community Conference Room	3rd Friday	1:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Every Monday	3:00 PM	Nancy Dunaway	417.556.8760
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816.861.4700 x56765
Kirkwood	St. Louis	First Presbyterian Church of Kirkwood 100 E. Adams Ave., Room 009	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW Patty Waller	314.286.2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314.372.2369
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	573.201.7300
South County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider Amanda Landsbaum, OT	314.846.5919 636.778.3377
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Groomes, RN	636.926.3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573.543.2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283 660.485.6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:00 PM	Carol Weber	314.713.4820
Webster Groves	St. Louis	Bethesda Orchard - Parlor Room 21 North Old Orchard Ave.	Last Friday	10:30 AM	Laurel Willis, MSG	314.471.6302

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



Illinois Support Group Calendar

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

СІТҮ	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	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, MD	618.549.7507
Carlinville	Macoupin	Carlinville Area Hospital Medical Office Building-Community Room 20613 N. Broad St.	3rd Wednesday contact leader to verify date and time.	10:00 AM	Amy Murphy, PT	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
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 Street	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Lin Smith Mary DeLong	618.344.0680 217.204.2137
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut–Meeting Room 2	1st Wednesday April-December	6:00 PM	Larry and Karen Ladd	217.377.4973
Nashville	Washington	Washington County Hospital 705 S. Grand Ave., Conference Room	4th Friday	1:00 PM	Helen Quaid	618.493.6064
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	3rd Sunday Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.483.4300
Quincy	Adams	Quincy Public Library 526 Jersey St.	1st or 2nd Saturday contact leader to verify date and time	10:30 AM	Terri and Dave May	217.224.7027
Quincy For Caregivers Only	Adams	Quincy Public Library 526 Jersey St.	2nd Thursday 4th Tuesday contact leader to verify date and time	12:30 PM	Terri and Dave May	217.224.7027

Non-affiliated support groups are listed on our website only



Illinois Exercise Classes

Continued on page 15

CITY	MEETING SITE	LEVEL	DAY OF MEETING	TIME	LEADER(S)	PHONE
Belleville	Exercise for Parkinson's (cycle + strength) East Belleville YMCA, 2627 Carlyle Avenue	Level 1	Wednesday	12:00 PM	Stefanie McLaughlin	618.236.9983 (registration)
Carlinville	Movement Training Carlinville Area Hospital, Medical Office Building, Community Room, 20613 N. Broad	Level 2	Thursday	10:00 AM	Amy Murphy, PT	217.854.3141 x377
O'Fallon	Exercise for Parkinson's (cycle + strength) O'Fallon YMCA, 284 North Seven Hills Road	Level 1	Tuesday Thursday	12:00 PM	Amy Weisbrodt	618.628.7701 (registration)
Springfield	Joy of Movement (dance) First Presbyterian Church, 321 South 7th Street	All Levels	Tuesday Thursday	1:30 PM	Eve Fischberg, OT	217.494.4961

LINK NOVEMBER 2018 VOLUME 32, ISSUE 4



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 classes are available at all times on our website. New classes are bold. 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 Road	Level 2	Thursday	10:30 AM	Roxanne Maier	636.778.3377 (registration)
Chesterfield	50-50 Fusion 1415 Elbridge Payne, Ste. 163	Level 3	Wednesday	1:00 PM	Alana Krone	636.778.3377
Chesterfield	Movement Training St. Luke's Outpatient Center, 111 St. Luke's Center Drive Bldg. B, Suite 14B	Level 1	Monday	10:00 AM	Ann Towey, PTA	314.205.6934 (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	1:30-2:15 PM 11:30 AM-12:15 PM	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 11:30 AM	Craig Miller	636.778.3377
*Chesterfield	Indoor Cycling CycleBar, 1657 Clarkson Rd.	Level 2-3	Tuesday	1:00 pm	Alana Krone	636.778.3880 (registration)
Chesterfield	Exercise for Parkinson's (cycle + strength) Chesterfield YMCA , 16464 Burkhardt Place	Level 2	Friday	12:30 PM	Angela Weaver	636.532.3100 (registration)
Clayton	Fit 'n Fun The Center of Clayton, 50 Gay Ave., Mind/Body Room	Level 1	Wednesday Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
*Creve Coeur	Box Your B.E.S.T. The J's Staenberg Family Complex, 2 Millstone Campus Dr.	Level 3	Tuesday Thursday	1:00 PM	Joe Ryan	314.442.3452 (registration)
Creve Coeur	Parkinson's Performance (small group training) JCC Staenberg Family Complex, 2 Millstone Campus Drive	Level 3	Saturday Weekday TBD	TBD	Sabra Boes	636.778.3377 (registration)
Florissant	Movement Training Garden Villas North, 4505 Parker Rd.	Level 1	Thursday	10:00 AM	Nancy Robb	314.869.5296
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)
Oakland	Movement Training Bethesda Hawthorne Place, 1111 S. Berry Road	Level 1-2	Thursday	1:45 PM	Teresa Godfrey, PT	314.942.5750 (registration)
O'Fallon	Movement Training Park Place at WingHaven, Independent Living Fitness Room, 2002 Boardwalk Place Dr	Level 1	Wednesday	10:00 AM	Marina Clements, PT	636.778.3377
South St. Louis County	Fit 'n Fun Garden Villas South, 13457 Tesson Ferry Rd.	Level 1	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
South St. Louis County	Movement Training Friendship Village Sunset Hills, 12563 Village Circle Drive	Level 2	Friday	10:00 AM	Marina Clements, PT	636.778.3377
*St. Louis	Circuit Training Paraquad Health & Wellness Center, 5200 Berthold Ave.	Level 2-3	Thursday	10:00 AM	Melissa Smith, OTR/L	314.289.4202 (registration)
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	Holly Evans, COTA	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 Maryville University, 650 Maryville University Dr. Walker Building-Community Room		Thursday	1:30 PM	Megan Moran, MT	636.778.3377 (registration)
Washington	Exercise for Parkinson's (cycle + strength) Four Rivers YMCA , 400 Grand Avenue	Level 1	Tuesday Thursday	1:00 PM	Tim Peters	636.239.5704 (registration)

^{*}If you have a need for a scholarship for any exercise class listed on this page that charges a fee for participation, 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.



Soon! A NEW class that meets twice a week, Saturdays and mid-week, at the J's Staenberg Family Complex in Creve Coeur. Work with a personal trainer in a small group setting to improve your balance, strength, flexibility, coordination and cardiovascular fitness. Each month long training block is designed to improve your fitness level while teaching you how to use the equipment in a gym setting to maximize your function. You will learn how use treadmills, bikes, weight machines and much more. Class size will be limited, so call 636.778.3377 to pre-register.

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!



Strength in optimism. Hope in progress.

GREATER ST. LOUIS CHAPTER

GREATER ST. LOUIS CHAPTER

1415 Elbridge Payne Road, Suite 150 Chesterfield, Missouri 63017 Address Service Requested Non-Profit Org. U.S. Postage PAID Permit #1032



INFORMATION:

apdastlouis@apdaparkinson.org

WEBSITE:

www.apdaparkinson.org/greaterstlouis

EMAII.

Debbie Guyer, Executive Director dguyer@apdaparkinson.org

Tricia Creel, Wellness Coordinator tcreel@apdaparkinson.org

Amanda Landsbaum, Wellness Coordinator alandsbaum@apdaparkinson.org

Melissa Skrivan, Director of Development mskrivan@apdaparkinson.org

Meredith Wallus, Office Coordinator mwallus@apdaparkinson.org



On March 14, 2019, the APDA-Greater St. Louis Chapter will once again offer a Midwest Parkinson Congress.

This year's program will feature Rebecca Gilbert, MD, PhD, Chief Scientific Officer of the American Parkinson Disease Association, and participants can then select from three tracks to attend: Research & Medications, Care Partner Resources and a Managing Your Disease track. The Congress will start at 1:00 pm and conclude at 4:45 pm. In addition, we are pleased to offer a track in the evening for a young- onset program, featuring Dr. Paul Short, from 6:30-8:30 pm.

The Congress will be held at Congregation Shaare Emeth, 11645 Ladue Road, in west St. Louis County. Stay tuned for further details and an invitation/agenda which will follow after the New Year.