LETTER FROM THE EXECUTIVE DIRECTOR

It’s very difficult to decide what articles to use in our quarterly newsletters, mostly because the LiNK is mailed to 11,000 homes and businesses and is read by individuals who represent the whole spectrum of Parkinson disease, from beginning to end. In this issue, we’re presenting some topics that are challenging to deal with and hard to even think about—but in an effort to prepare you as well as address the needs of those who are further down the road on their journeys, it is necessary to discuss them.

As you read this issue of the LiNK, please remember what we say in PD101: Parkinson’s is very unique and the course of each person’s disease looks different from every other person’s. No two people exhibit the same cluster of symptoms or same disease progression—Parkinson’s is truly a “snowflake” disease. Looking around at all of the 700 attendees of our recent Midwest Parkinson Congress made that evident!

Enjoy learning and enjoy being a part of such a vibrant organization where you are never alone. We are here to guide you on your journey and to be inspired by you – to accompany you through the triumphs and the trials. Join us for exercise and at support group meetings, at the golf tournament dinner in May, at our PEP meetings in August and November, at the Stein Speaker Series in September, and at the Optimism Walk in October. This year will be another one for the record books. We appreciate your support always.

See you soon,

Debbie
In spite of winds in excess of 50 mph, the second annual Midwest Parkinson Congress took place in West St. Louis County (not Kansas or Oz) with attendance exceeding 700, a filled Resource Room of displays and exhibits, and a lobby featuring premier sponsors. Leslie Chambers, President and CEO of the American Parkinson Disease Association (APDA), welcomed the audience. She reminded us that the APDA’s dual mission is to provide services and support to individuals with Parkinson disease (PD) and their families/care partners and to support research to ultimately find a cure for PD. “We are so very proud of the work here at our Greater St. Louis Chapter in support of our mission. This chapter has a long history of providing excellent services to the community and for supporting APDA research both nationally and here at Washington University. This year the chapter will be celebrating their 35th anniversary and I’d like to thank many of you who have been our supporters over the years for your ongoing dedication to helping the chapter develop and provide these programs and services.” Dr. Rebecca Gilbert, VP and Chief Scientific Officer of the American Parkinson Disease Association, delivered the keynote address which provided hope to an audience comprised of individuals from across the bi-state region and from as far away as California and Texas. Dr. Gilbert not only explained how new treatments come to be, but she identified new treatments in the pipeline, including:
a) Removing/inhibiting alpha-synuclein aggregation through alpha-synuclein vaccines or other molecules that prevent alpha-synuclein clumping

b) Exploring neuroprotective strategies—drugs such as Isradipine, GDNF, stem cell therapies, and exercise

c) Studying mutation specific strategies including GBA and LRRK2

d) Expanding dopamine delivery systems such as the accordion pill and a new COMT inhibitor

Three break-out sessions immediately followed Dr. Gilbert’s presentation. The first one included Dr. Joel Perlmutter’s session on Defining Dystonia and Treatment and simultaneously, in another room, Christine Alsop’s session on Planning for the Future. Next, Dr. Brad Racette spoke about Unraveling the Mysteries of PD which explained how his laboratory uses large administrative datasets to investigate Parkinson disease prediction, associations, and health service utilization. Simultaneously, down the hall, Johanna Hartlein’s session addressed The Ins and Outs of PD Meds including side effects and tips for taking medications. The third break-out sessions were given by Dr. Meghan Campbell, who spoke on cognitive decline in PD in one room, while Dr. Bob Cunningham spoke about assistive technology, describing a variety of devices and strategies that can be used by people with Parkinson disease to assist them in the use of computers, tablets, or smartphones.

The presenters in the second and third break-out sessions had to contend with an extended power outage but were remarkable and spoke to over 300 people in their respective audiences without a microphone or slide set to augment their presentations. You can view their power point presentations, which have been uploaded to our website, www.apdaparkinson.org/greaterstlouis

Our gratitude also extends to those who participated in the Young Onset Parkinson Disease (YOPD) track which began at 6:30 PM (with the electricity back on) with Dr. Rebecca Gilbert discussing what defines YOPD. She addressed the unique concerns and challenges that face people who are

Continued on Page 6
When most people think of Parkinson’s, they think of the motor symptoms that often come with it: tremor, rigidity, slowness, and shuffling. However, they are often unaware that Parkinson’s comes with a wide variety of non-motor symptoms that can affect thinking, mood and behavior as well.

Parkinson disease psychosis (PDP) is a non-motor symptom of Parkinson’s that causes people to experience hallucinations and/or delusions. Approximately 50% of all people living with Parkinson’s will experience some form of hallucinations or delusions, and the longer one lives with Parkinson disease, the greater the likelihood they’ll experience them.

What causes Parkinson disease psychosis?

Parkinson’s is a brain disorder associated with a loss of dopamine-producing nerve cells (neurons) deep inside the brain. Dopamine is a neurotransmitter (a chemical substance) that helps regulate the body’s movement, and it also allows us to think clearly and regulate our emotions. When you try to replace the dopamine that’s been lost in a person with Parkinson’s, it can disrupt the system, which can impact thinking, visual processing and more. PDP can therefore be a symptom of the disease itself or a side effect of the medications used to manage it.

As a result, it’s an ongoing balancing act for doctors treating Parkinson’s to prescribe enough dopamine to control a person’s motor symptoms, but not so much that the person experiences hallucinations and/or delusions.

What makes some people with Parkinson’s more susceptible to PDP?

Not everyone living with Parkinson’s will experience hallucinations and/or delusions, but there are several things that can increase your risk. Here are a few to look out for. Be sure to speak to your doctors and care partners if you notice any changes.

› Decline in memory
› Increased cognitive impairment
› Increased motor symptoms and disabilities unrelated to Parkinson’s
› History of depression
› Increased sleep disturbances such as REM Sleep Behavior Disorder, sleep apnea, vivid dreaming and sleep interruptions
› Vision problems such as blurry or double vision
› Hearing problems
› Aging (it’s common for people to experience vision and hearing problems as they age so the older one gets, the more likely they will be affected by hallucinations)
› Medication changes such as new medications, dosage changes and drug interactions
› Disease progression (70% of people who have been living with Parkinson’s for over 20 years will experience PDP)
What are hallucinations?

A hallucination is something someone sees, hears, smells, tastes or feels that’s not actually there. Essentially, they are tricks that the brain plays on the senses. It’s estimated that about 50% of people with Parkinson’s experience some type of hallucination over the course of having the disease. Most of the time these hallucinations are visual in nature.

For example, one person reported that he often sees tiny people along the floorboards in his kitchen. Another one said he sees people who aren’t there when he walks into a certain room of his house. One doctor shared that a patient regularly mistook her laundry piles for a person.

These visions appear clear as day to the person with Parkinson’s but cannot be seen by anyone else. In some cases, the visions may be disturbing and cause emotional distress, but that’s not always the case. They may be friendly and not bothersome at all.

When people with Parkinson’s first start experiencing hallucinations, they typically experience them with insight. This means that they know what they are seeing isn’t real, and they’re able to recognize it as a symptom of living with Parkinson’s.

On the other hand, when people lose insight, they begin to believe that the hallucinations are real. They may start talking to them, interacting with them and even try to draw their care partner into the scene with them. When their hallucinations reach this stage, they can go on for a very long time and cause hyper-agitation and aggressiveness, which can be very difficult for the care partner to witness and manage.

In addition, whether the hallucinations are distressing or not, just interacting with them can pose a potential risk of harm to the person with Parkinson’s or anyone else in the room.

What are delusions?

Delusions are specific and fixed beliefs that are very real and true to the person experiencing them. They can contradict all semblance of reality and rational thought, but no amount of convincing can change what the person believes is true. Additionally, if you try to convince someone experiencing a delusion that it’s not true, they can become suspicious and doubt you which makes an already difficult situation even worse.

Delusions happen much less frequently than hallucinations. Only about 10% of people with Parkinson’s experience them, but because they’re often ongoing, involuntary and feel very real to the person, they can be much more difficult to manage and treat.

The most common delusions people with Parkinson’s experience are:

» The belief that their spouse is being unfaithful
» The belief that their care partner is poisoning them with their medications
» The belief that people are stealing from them

Fortunately, many people with Parkinson’s have found ways to treat and manage the symptoms of Parkinson disease psychosis.

What’s the treatment for Parkinson disease psychosis?

The single most important thing to do when it comes to PDP is to tell your care providers and partners the minute you notice changes in your vision, hearing, thinking and behavior. The earlier they know what’s going on, the sooner they can begin interventions to help you feel better.

Once you bring your concerns up to your doctor, he or she will typically do a clinical evaluation, review your medications and dosage, assess your lifestyle and determine the severity of your symptoms. Depending upon what he/she finds, your doctor may refer you to counseling or therapy, adjust your medication, change your medication, eliminate medication or do all of the above. If none of those strategies work, your doctor may try antipsychotic drug therapy to see if he/she can adjust chemical levels in the brain. This can bring with it an entirely different set of problems, so it’s important to be invested every step along the way and be sure you’re well-informed before you move in that direction.

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

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Continued from Page 3

diagnosed with PD before the age of 50. A panel of YOPD experts followed with a discussion of when and how to disclose diagnosis (Terri Hosto, LSCW, MSW), job accommodations (Debbie Turley, OTR/L) and workplace rights and considerations when filing for disability (Janine M. Martin, JD). The evening concluded with a panel of YOPD individuals/spouses. Mike and Melody Mylenbusch and Cathy Combs discussed their very personal experiences, which touched everyone deeply.

I have received numerous calls from individuals wanting to know how to subscribe to Dr. Rebecca Gilbert’s blog on the national APDA website, so I am providing that link here: [https://www.apdaparkinson.org/doctor-blogs/a-closer-look/](https://www.apdaparkinson.org/doctor-blogs/a-closer-look/). The blog, called *A Closer Look*, aims to address both timely and timeless topics related to Parkinson disease. In addition, it focuses on practical, take-home tips that can be gleaned from the information discussed. We encourage you to subscribe to the blog and suggest blog topics. One of our active members, Bill Sorrell, commented, “What a treasure to be able to get more insights from Dr. Gilbert!” I know you’ll agree with Bill.

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Guidelines for Knowing when to Consider Hospice

Medicare has specific criteria for hospice admission. Here are some problems a person with PD might be experiencing that would be clues that hospice may be appropriate:

- Inability to dress, bathe, or feed oneself
- Incontinence
- Inability to communicate well
- Multiple hospitalizations or ER visits
- Development of other problems such as pneumonia, urinary tract infections, sepsis, bed sores, or recurrent fever
- Weight loss (10% in the last six months is significant)
- Swallowing problems, needing to change food consistency
- Inability to walk without assistance
- Other co-occurring severe medical conditions
- Dementia
- Rigidity
- Increase in sleeping or severe fatigue

As Parkinson disease (PD) naturally progresses, there may come a time when even the best medical interventions no longer provide relief of symptoms. People with PD may find themselves having difficulty swallowing or maintaining their weight, getting infections, needing hospitalization, falling, or otherwise requiring assistance. Caregivers can become overwhelmed, struggling with the challenges of balancing the usual demands of life with the increasing demands physically, emotionally, and financially of caring for someone with advanced Parkinson’s. Families are often frustrated by a lack of resources to provide quality care. When the time comes that a person’s needs have grown, treatment is not providing enough relief, and the desire for more aggressive attempts at care is waning, it may be time to consider hospice care.

(Stacey Barton, MSW, LCSW, Clinical Social Worker, Department of Neurology, Washington University School of Medicine – excerpt from St. Louis APDA Link May, 2011)

Hospice can offer people with advanced Parkinson disease valuable support to help them stay in their homes or nursing facilities and support their families while avoiding unnecessary hospitalizations and improving their quality of life. Hospice care consists of a team including nurses, doctors, social workers, pastoral care workers, and many others all with extensive training in managing symptoms at end-of-life. One question individuals and families affected by Parkinson disease ask me in my role as Chief of the Division of Palliative Medicine at Washington University is how do you know when hospice care is right for you?

PD is one of the most challenging conditions to accurately predict a prognosis. Common signs that indicate progression into the advanced stages include losing the ability to walk and perform self-care activities such as dressing, bathing, and

Continued on Page 11
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Carol Heddingtonhaus  
Anne & Patrick Henning  

Kathleen Holas  
Linda & Steve Kilgore  

Cheryl & Martin Kinert  
Mr. & Mrs. Patrick King  

Nancy & Mike Klein  
Patricia & Mayer Levy  

Freda Lohr  
Mary Malik  

Jeanne & Philip McDermott  
Mary McCoy  

Jud & John Nassif  
Alice & Andre Nutis  

Annette Owings  
Roger Peters  

Patricia & Glenn Phillips  
Kathleen Roros  

Susan & John Rothenheber  
Diane & Karl Schoenfeld  

Kathy & Doug Schroeder  
Scott Seddon  

Brenda Shipp  
Cindy & David Smalley  

Edie & Rob Smith  

$500-$1,999  
Mary Carpenter & Phil Estep  

Amy & Bill Hillender  

ANNUAL GIVING  

Up to $99  
Mary & Robert Berneking  
Constance Dankmyer  

Marie Dealey  
Denna & James Drew  

Doris Ebersole  
John Jaeger  

Edith Kepfensteiner  
Linda & Bill Kennedy  

Freda Lohr  
Kathleen Overkamp  

Margie & Dewain Reimer  
Laurie, Alan &  

Aliza Dien Yaillen  

$100-$499  
Jo Alessandri  
Joan & Brian Elliott  

Richard Ellison  
Michelle Gauthier  

Charles Kohlenberger  
Diane & Donald Lange  

Linda & Lewis Miles  
Gary Moeller  

Martha & Tom Monahan  
Marilyn & Ron Oster  

Christy & Bob Pratzel  
Dennis Punicelli  

Mr. & Mrs. Albert Rotskoff  
Mary K. Weerts  

$500-$1,999  
Joanne & Mark Goldstein  
Margaret Lashley  

Hannah & Herl Locks  
Stephen Muench  

Jack R. Strosnider, Sr.  

$5,000-$9,999  
Anne Herron  
Scott Lentin Fund
Connecting Through Art is a **new creative arts program** that offers people with Parkinson disease (PD) the space and ability to express feelings, emotions, and daily concerns through drawing and painting. The program encourages participants to socialize as they participate in art activities and also helps them improve their fine motor skills. It is open to any adult who has been diagnosed with PD and their care partner, friend or family member.

The Art Cart was created in 2014 by Saba Shahid. The **Smile Through Art** curriculum is designed to improve fine and gross motor skills, enhance mood, combat tremors and rigidity, and improve handwriting. Saba encourages participants to release the artist within, as art promotes mental stimulation, improving concentration and mindfulness. Art promotes development of fine motor skills as participants grasp a paintbrush and focus on a steady hand. Art promotes relaxation and makes you smile, as you feel relaxed and accomplished. And making art is fun! In making art, there are no mistakes, so first time artists are always welcome.

The program’s first activity is an art class with instruction provided by The Art Cart’s **Smile Through Art** workshop. Complimentary refreshments will be provided. The program is free, but registration is required and space is limited.

Contact the APDA Resource Center at 636.778.3377 for further information or to register for the two-hour session being offered on July 22 from 10:00 AM – 12:00 noon at a location to be determined (at press time).

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**APDA — GREATER ST. LOUIS CHAPTER**

**FREE!**

**July 22nd, 10AM–NOON**

**registration required**

The Smile Through Art curriculum is designed to improve fine and gross motor skills, enhance mood, combat tremors and rigidity, and improve handwriting.

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**Continued from Page 7**

Toileting. People in this stage may have dementia and hallucinations. They often lose their ability to speak clearly. Individuals may experience increased coughing with feeding and require their food to be pureed. Their poor nutritional and functional status places them at high risk for skin breakdown and pressure ulcers. In addition, they may develop fevers and increased shortness of breath, and even require emergency room visits or hospitalization for infections including pneumonia or blood stream infections called sepsis.

If you or a loved one experiences these symptoms, talk to your physician to see if hospice is the right choice for you. Hospice doctors will review the medical chart to evaluate how quickly the disease is progressing. They will examine key areas like weight loss and may even check laboratory blood tests like albumin to find supporting evidence about their nutritional status. Given how challenging it is to determine a six-month prognosis in individuals with Parkinson disease, they may contact the person’s neurologist and/or primary care provider to obtain more information. They will also speak with the individual and family to determine the person’s goals, which for hospice candidates are typically to spend more time with their friends and family and less time in the hospital or intensive care unit.

It can be difficult to broach the subject of hospice with family. There is help available for these discussions, and it is acceptable to ask your doctor or other healthcare providers about this option for you or your loved one. Oftentimes, people would like the care to be delivered, but are hesitant to bring up these sensitive issues. Individuals and families should be aware of several options to obtain more information. One common way is to start with the person’s primary care physician, neurologist, or geriatrician. A second way is to schedule a palliative care appointment or a hospice informational visit where they can simply learn more information about the program and the benefits of hospice without any commitment. Hospice is not giving up – it is about providing the best care possible in the absence of a cure. For individuals and families interested in learning more about hospice eligibility and support, I can be reached at pwhite@wustl.edu.
The American Parkinson Disease Association (APDA) - Greater St. Louis Chapter is hosting our annual Optimism Walk on October 19, 2019 at Logan University in Chesterfield, MO. This annual event is part of a nationwide series of Optimism Walks that inspire people to step up and help put an end to Parkinson disease (PD). There are approximately one million people living with PD in the United States, with more being diagnosed every day. By raising funds and awareness, each and every participant in the Optimism Walk is helping to make a difference for those living with the disease today.

The Optimism Walk offers you an opportunity to share your Parkinson’s journey with your friends and family as you build your team. Create your walk page today at https://www.apdaparkinson.org/get-involved/optimism-walks/ to share the story of why you walk along with a photo if available, and ask your friends and family to join you on October 19 for a short walk and other family-friendly activities. If you need help registering, just call our office at 636.778.3377 and we will be happy to assist you in setting up your page.

“There is strength in numbers and when we see friends and families come together at the Optimism Walk, year after year, we are reminded of how important that strength can be,” said Debbie Guyer, Executive Director. “When someone you love is diagnosed with Parkinson’s, it can be frustrating to not know how to help. But then we see that frustration turn into motivation, determination and purpose when people take part in the Optimism Walk. We hear from participants who feel proud to have made a difference and who have done their part by raising critical funds that will enable APDA to provide more programs and services right here for our local PD community. Seeing the generations of families together enjoying a morning of festivities is awesome. This is truly one of the most inclusive events of the year.”

The Aging Life Care Association (ALCA) – STL hosted their first trivia night on November 2, 2018, and attracted a crowd of over 200 participants. The organization wanted to give back to the local community while raising awareness of what a professional in ALCA can provide. Over $7,000 was raised at the event, and ALCA donated $1,000 of those funds to the American Parkinson Disease Association (APDA) – Greater St. Louis Chapter.

ALCA is comprised of professionals who work together to provide client-centered care to individuals who are aging and to those with ongoing health needs. ALCA professionals provide expertise in areas such as health and disability, finances, housing and family support, local resources, advocacy, legal guidance, and crisis intervention.

The trivia committee consisted of ALCA members Nichole Huffman (Chair), Steve Miskovic (Co-Chair), Joey Boime, Allen Serfas, Carrie Burggraf, Katie Worzel, and Ndeye Ceesay. Their goal is to continue to host a trivia night annually while raising funds to support resources available in the community. We wish them success and look forward to continued collaboration.
Missouri Support Group Calendar

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

<table>
<thead>
<tr>
<th>CITY</th>
<th>COUNTY</th>
<th>MEETING SITE</th>
<th>DAY OF MEETING</th>
<th>TIME</th>
<th>LEADER(S)</th>
<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ballwin</td>
<td>St. Louis</td>
<td>Meramec Bluffs Care Center 1 Meramec, Veterans Rm.</td>
<td>4th Tuesday</td>
<td>2:30 PM</td>
<td>Chaplain Chris Nilges</td>
<td>636.923.2338</td>
</tr>
<tr>
<td>Cape Girardeau</td>
<td>Cape Girardeau</td>
<td>Cape Girardeau Public Library 711 N Clark Street</td>
<td>4th Monday</td>
<td>6:00 PM</td>
<td>Desma Reno, RN, MSN</td>
<td>573.651.2678</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>APDA Community Resource Center 1415 Elbridge Payne, Suite 150</td>
<td>1st Tuesday</td>
<td>11:00 AM</td>
<td>Tricia Creel, PT</td>
<td>636.778.3377</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>APDA Community Resource Center 1415 Elbridge Payne, Suite 150</td>
<td>2nd Monday</td>
<td>10:30 AM</td>
<td>Jay Bender, Lynda Wiens</td>
<td>636.778.3377</td>
</tr>
<tr>
<td>De Soto</td>
<td>Jefferson</td>
<td>StoneBridge – The Villas 1550 Villas Drive</td>
<td>Last Wednesday</td>
<td>3:00 PM</td>
<td>Jennie Lessor</td>
<td>636.586.6559</td>
</tr>
<tr>
<td>Festus/</td>
<td>Crystal City</td>
<td>Disability Resource Association 130 Brandon Wallace Way</td>
<td>3rd Tuesday</td>
<td>1:00 PM</td>
<td>Penny Roth, Laura Sobba</td>
<td>636.931.7696  x129</td>
</tr>
<tr>
<td>Florissant</td>
<td>St. Louis</td>
<td>Garden Villas North 4505 Parker Rd.</td>
<td>4th Thursday</td>
<td>11:00 AM</td>
<td>Nancy Robb</td>
<td>314.869.5296</td>
</tr>
<tr>
<td>Jefferson City</td>
<td>Cole</td>
<td>Capital Region Medical Center Community Conference Room 1125 Madison St.</td>
<td>3rd Friday</td>
<td>1:00 PM</td>
<td>Jennifer Urich, PT David Urich</td>
<td>573.632.5440  573.796.2395</td>
</tr>
<tr>
<td>Joplin</td>
<td>Jasper</td>
<td>Mercy Hospital 100 Mercy Way Conference Room</td>
<td>Every Monday</td>
<td>3:00 PM</td>
<td>Nancy Dunaway</td>
<td>417.556.8760</td>
</tr>
<tr>
<td>Kansas City</td>
<td>Jackson</td>
<td>VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room</td>
<td>3rd Tuesday</td>
<td>11:00 AM</td>
<td>Jesus Torres, Nikki C. Caraveo, RN, BSN, CNRN</td>
<td>816.861.4700 x57675</td>
</tr>
<tr>
<td>Kirkwood</td>
<td>St. Louis</td>
<td>First Presbyterian Church of Kirkwood 100 E. Adams Ave., Room 009, Lower Level</td>
<td>4th Tuesday</td>
<td>7:15 PM</td>
<td>Terri Hosto, MSW, LCSW Patty Waller</td>
<td>314.286.2418</td>
</tr>
<tr>
<td>Ladue</td>
<td>St. Louis</td>
<td>The Gatesworth 1 McKnight Place, Lower level</td>
<td>2nd Wednesday</td>
<td>1:00 PM</td>
<td>Maureen Neusel, BSW</td>
<td>314.372.2369</td>
</tr>
<tr>
<td>Poplar Bluff</td>
<td>Butler</td>
<td>Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3</td>
<td>2nd Monday</td>
<td>6:00 PM</td>
<td>Charles Hibler, register with Beryl or Dana</td>
<td>573.785.6222 855.444.7276 573.776.9355</td>
</tr>
<tr>
<td>Rolla</td>
<td>Phelps</td>
<td>Phelps Health, 1000 W. 10th St. Private Dining Rm #1</td>
<td>4th Thursday</td>
<td>2:30 PM</td>
<td>Sarah Robinson</td>
<td>573.201.7300</td>
</tr>
<tr>
<td>South County</td>
<td>St. Louis</td>
<td>Garden Villas South 13457 Tesson Ferry Rd.</td>
<td>2nd Wednesday</td>
<td>10:00 AM</td>
<td>Jack Strosniider, Amanda Landsbaum, OT</td>
<td>314.846.5919 636.778.3377</td>
</tr>
<tr>
<td>St. Peters</td>
<td>St. Charles</td>
<td>Spencer Road Library 427 Spencer Rd., Room 259</td>
<td>1st Tuesday</td>
<td>1:00 PM</td>
<td>Jody Peterson, OTA Jessica Womack</td>
<td>636.724.4357</td>
</tr>
<tr>
<td>Trenton</td>
<td>Grundy</td>
<td>Royal Inn 1410 E. 9th Street</td>
<td>1st Thursday</td>
<td>10:00 AM</td>
<td>Novy &amp; Mary Ellen Foland Gloria Koon</td>
<td>660.357.2283</td>
</tr>
<tr>
<td>Washington</td>
<td>Franklin</td>
<td>Washington Public Library 410 Lafayette Avenue</td>
<td>2nd Monday</td>
<td>6:00 PM</td>
<td>Carol Weber</td>
<td>314.713.4820</td>
</tr>
<tr>
<td>Webster Groves</td>
<td>St. Louis</td>
<td>Bethesda Orchard - Parlor Room 21 North Old Orchard Ave.</td>
<td>Last Friday</td>
<td>10:30 AM</td>
<td>Laurel Willis, MSG</td>
<td>314.471.6302</td>
</tr>
</tbody>
</table>

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.

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</tr>
</thead>
<tbody>
<tr>
<td>Alton</td>
<td>Madison</td>
<td>Senior Services Plus, 2603 N. Rodgers Ave.</td>
<td>3rd Tuesday</td>
<td>2:00 PM</td>
<td>Dustin Heiser</td>
<td>618.465.3298x120</td>
</tr>
<tr>
<td>Belleville</td>
<td>St. Clair</td>
<td>Southwestern Illinois College Programs and Services for Older Persons 201 N. Church St.</td>
<td>2nd Monday</td>
<td>1:30 PM</td>
<td>Jodi Gardner, MSW, LCSW</td>
<td>618.234.4410x7031</td>
</tr>
<tr>
<td>Carbondale</td>
<td>Jackson</td>
<td>Prairie Living at Chautauqua 955 Villa Ct. West building, 3rd floor</td>
<td>1st Wednesday</td>
<td>1:00 PM</td>
<td>Bill Hamilton, MD</td>
<td>618.339.4159</td>
</tr>
<tr>
<td>Carlinville</td>
<td>Macoupin</td>
<td>Carlinville Area Hospital Medical Office Building-Community Room 20613 N. Broad St.</td>
<td>3rd Wednesday</td>
<td>10:00 AM</td>
<td>Amy Murphy, PT</td>
<td>217.854.3839</td>
</tr>
<tr>
<td>Centralia</td>
<td>Marion</td>
<td>Heritage Woods of Centralia 2049 E. McCord St.</td>
<td>2nd Wednesday</td>
<td>2:00 PM</td>
<td>Betty Evans, Helena Quaid</td>
<td>618.533.0224, 618.493.6064</td>
</tr>
<tr>
<td>Champaign</td>
<td>Champaign</td>
<td>Savoy United Methodist Church 3002 W. Old Church Road</td>
<td>Every Monday</td>
<td>10:00 AM</td>
<td>Carol and Butch Clark, Dave and Monica Matakas</td>
<td>217.898.2725, 217.720.2016</td>
</tr>
<tr>
<td>Charleston</td>
<td>Coles</td>
<td>LifeSpan Center 11021 E. Co. Rd. 800N</td>
<td>Last Tuesday</td>
<td>1:30 PM</td>
<td>Jean Shobe, Jean Penrod</td>
<td>217.639.5150</td>
</tr>
<tr>
<td>Decatur</td>
<td>Macon</td>
<td>Westminster Presbyterian Church 1360 West Main Street</td>
<td>3rd Thursday</td>
<td>1:30 PM</td>
<td>John Kileen</td>
<td>217.620.8702</td>
</tr>
<tr>
<td>Edwardsville</td>
<td>Madison</td>
<td>Edwardsville YMCA 1200 Esic Dr.</td>
<td>1st Tuesday (starting June 4)</td>
<td>12:00 PM</td>
<td>Pam Pinegar</td>
<td>618-656-0436</td>
</tr>
<tr>
<td>Highland</td>
<td>Madison</td>
<td>St. Joseph's Hospital, 12866 Troxler Ave, Sullivan Conference Room</td>
<td>4th Tuesday</td>
<td>2:00 PM</td>
<td>Kayla Toennies, OT Oliva Hodges, SLP</td>
<td>618.651.2720</td>
</tr>
<tr>
<td>Jacksonville</td>
<td>Morgan</td>
<td>Passavant Area Hospital 1600 W. Walnut-Meeting Room 2</td>
<td>1st Wednesday</td>
<td>6:00 PM</td>
<td>Larry and Karen Ladd</td>
<td>217.377.4973</td>
</tr>
<tr>
<td>Nashville</td>
<td>Washington</td>
<td>Washington County Hospital 705 S. Grand Ave., Conference Room</td>
<td>4th Friday</td>
<td>1:00 PM</td>
<td>Helen Quaid</td>
<td>618.493.6064</td>
</tr>
<tr>
<td>Springfield</td>
<td>Sangamon</td>
<td>St. John’s Rehab. @ Fit Club South 3631 S. 6th. Street #C</td>
<td>3rd Sunday Odd numbered months: 1,3,5,7,9,11</td>
<td>2:00 PM</td>
<td>Kelly Neumann, PT</td>
<td>217.814.8165</td>
</tr>
<tr>
<td>Quincy</td>
<td>Adams</td>
<td>Quincy Public Library 526 Jersey St.</td>
<td>1st or 2nd Saturday contact leader to verify date and time</td>
<td>10:30 AM</td>
<td>Terri and Dave May</td>
<td>217.224.7027</td>
</tr>
<tr>
<td>Quincy</td>
<td>Adams</td>
<td>Quincy Public Library 526 Jersey St.</td>
<td>2nd Tuesday 4th Tuesday contact leader to verify date and time</td>
<td>12:30 PM</td>
<td>Terri and Dave May</td>
<td>217.224.7027</td>
</tr>
</tbody>
</table>

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

**Illinois Exercise Classes**

<table>
<thead>
<tr>
<th>CITY</th>
<th>MEETING SITE</th>
<th>LEVEL</th>
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<th>TIME</th>
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<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breese</td>
<td>Exercise for Parkinson's (cycle + strength) Clinton County YMCA, 14160 Jamestown Road</td>
<td>Level 1</td>
<td>Monday Wednesday</td>
<td>2:00 PM</td>
<td>Jack Swank, Vicky White</td>
<td>618.526.5628 (registration)</td>
</tr>
<tr>
<td>Carlinville</td>
<td>Movement Training Carlinville Area Hospital, Medical Office Building, Community Room, 20613 N. Broad</td>
<td>Level 2</td>
<td>Thursday</td>
<td>10:00 AM</td>
<td>Amy Murphy, PT</td>
<td>217.854.3141 x377</td>
</tr>
<tr>
<td>Edwardsville</td>
<td>Movement Training Edwardsville YMCA, 1200 Esic Drive</td>
<td>All levels</td>
<td>Tuesday &amp; Friday</td>
<td>11:00 AM starts June 4, 2019</td>
<td>Ann McLean</td>
<td>618.656.0436 (registration)</td>
</tr>
<tr>
<td>*Highland</td>
<td>Exercise For Parkinson’s (cycle + strength) Korte Recreation Center, 1 Nagel</td>
<td>Level 2</td>
<td>Monday Wednesday</td>
<td>1:00 PM</td>
<td>Jinee McDonnell-Stewart, Ginger Kabureck</td>
<td>618.651.1386 (registration)</td>
</tr>
<tr>
<td>O’Fallon</td>
<td>Exercise for Parkinson’s (cycle + strength) O’Fallon YMCA, 284 North Seven Hills Road</td>
<td>Level 1</td>
<td>Tuesday Thursday</td>
<td>12:00 PM</td>
<td>Amy Weisbrodt</td>
<td>618.628.7701 (registration)</td>
</tr>
<tr>
<td>Springfield</td>
<td>Joy of Movement (dance) First Presbyterian Church, 321 South 7th Street</td>
<td>All Levels</td>
<td>Tuesday Wednesday Thursday</td>
<td>10:00 AM (W) 1:30 PM (Tu, Th)</td>
<td>Eve Fischberg, OT</td>
<td>217.494.4961</td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th>CITY</th>
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<th>LEADER(S)</th>
<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Brentwood</td>
<td>Tango Convergence Dance and Body Center, 8044 Manchester Road</td>
<td>Level 2</td>
<td>Thursday</td>
<td>10:30 AM</td>
<td>Roxanne Maier</td>
<td>636.778.3377</td>
</tr>
<tr>
<td></td>
<td>Chesterfield 50-50 Fusion 1415 Elbridge Payne, Ste. 163</td>
<td>Level 3</td>
<td>Wednesday</td>
<td>1:00 PM</td>
<td>Alana Krone</td>
<td>636.778.3377</td>
</tr>
<tr>
<td></td>
<td>Chesterfield Circuit/Interval Training 1415 Elbridge Payne, Ste. 163</td>
<td>Level 2-3</td>
<td>Monday, Tuesday, Thursday</td>
<td>2:30 PM, 10:00 AM, 1:00 PM</td>
<td>Tricia Creel, PT</td>
<td>636.778.3377</td>
</tr>
<tr>
<td></td>
<td>Chesterfield Movement Training 1415 Elbridge Payne, Ste. 163</td>
<td>Level 1</td>
<td>Monday</td>
<td>1:30 PM, 11:30 AM</td>
<td>Tricia Creel, PT</td>
<td>636.778.3377</td>
</tr>
<tr>
<td></td>
<td>Chesterfield Tai Chi 1415 Elbridge Payne, Ste. 163</td>
<td>Level 1</td>
<td>Tuesday</td>
<td>11:15 AM, 10:00 AM, 10:15 &amp; 11:30 AM</td>
<td>Craig Miller</td>
<td>636.778.3377</td>
</tr>
<tr>
<td></td>
<td>*Chesterfield Indoor Cycling CycleBar, 1657 Clarkson Rd.</td>
<td>Level 2-3</td>
<td>Tuesday</td>
<td>1:00 PM</td>
<td>Alana Krone</td>
<td>636.778.3880</td>
</tr>
<tr>
<td></td>
<td>Chesterfield Exercise for Parkinson’s (cycle + strength) Chesterfield YMCA, 16464 Burkhardt Place</td>
<td>Level 2</td>
<td>Wednesday</td>
<td>1:00 PM, 12:30 PM</td>
<td>Angela Weaver</td>
<td>636.532.3100</td>
</tr>
<tr>
<td></td>
<td>Clayton Fit ‘n Fun The Center of Clayton, 50 Gay Ave., Mind/Body Room</td>
<td>Level 1</td>
<td>Wednesday</td>
<td>2:00 PM</td>
<td>Mike Scheller, PTA</td>
<td>314.289.4202</td>
</tr>
<tr>
<td></td>
<td>*Creve Coeur Roll With the Punches The J’s Staanberg Family Complex, 2 Millstone Campus Dr.</td>
<td>Level 3</td>
<td>Tuesday</td>
<td>10:00 PM</td>
<td>Joe Ryan</td>
<td>314.442.3452</td>
</tr>
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<td></td>
<td>Florissant Movement Training Garden Villas North, 4505 Parker Rd.</td>
<td>Level 1</td>
<td>Thursday</td>
<td>10:00 AM</td>
<td>Nancy Robb</td>
<td>314.869.5296</td>
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<td></td>
<td>Ladue Tremble Clefs Choir Salem United Methodist, 1200 S. Lindbergh Blvd., Lower Level Choir Room</td>
<td>Saturday</td>
<td>1:30 PM</td>
<td>Linda McNair, MT-BC</td>
<td>636.778.3377</td>
<td></td>
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<tr>
<td>Maryland Heights</td>
<td>Exercise for Parkinson’s (cycle + strength) Edward Jones YMCA, 12521 Marine Ave</td>
<td>Level 1-2</td>
<td>Tuesday</td>
<td>12:00 PM</td>
<td>Martin Caupp</td>
<td>314.439.9622</td>
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<td></td>
<td>Oakland Movement Training Bethesda Hawthorne Place, 1111 S. Berry Road</td>
<td>Level 1-2</td>
<td>Thursday</td>
<td>1:45 PM</td>
<td>Teresa Godfrey, PT</td>
<td>314.942.5750</td>
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<td></td>
<td>O’Fallon Movement Training Park Place at Winghaven, Independent Living Fitness Room, 2002 Boardwalk Place Dr</td>
<td>Level 1</td>
<td>Wednesday</td>
<td>10:00 AM</td>
<td>Colleen Bock, PTA</td>
<td>636.233.2813</td>
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<td></td>
<td>South St. Louis County Exercise for Parkinson’s (cycle + strength) South County YMCA, 12736 Southfork Road</td>
<td>Level 1-2</td>
<td>Friday</td>
<td>10:30 AM</td>
<td>Diane Summers</td>
<td>314.849.9622</td>
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<td></td>
<td>South St. Louis County Fit ‘n Fun Garden Villas South, 13457 Tesson Ferry Rd.</td>
<td>Level 1</td>
<td>Monday</td>
<td>11:30 AM</td>
<td>Mike Scheller, PTA</td>
<td>314.289.4202</td>
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<td></td>
<td>South St. Louis County Movement Training Friendship Village Sunset Hills, 12563 Village Circle Drive</td>
<td>Level 2</td>
<td>Friday</td>
<td>10:00 AM</td>
<td>Marina Clements, PT</td>
<td>636.778.3377</td>
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<td></td>
<td>*South St. Louis County Circuit Training HouseFit, 3809 Lemay Ferry Road</td>
<td>Level 2-3</td>
<td>Tuesday &amp; Thursday</td>
<td>11:00 AM</td>
<td>Marina Clements, PT</td>
<td>314.339.7430</td>
</tr>
<tr>
<td></td>
<td>Ste. Genevieve Movement Training Community Center, 21390 Hwy 32</td>
<td>Level 2</td>
<td>Thursday</td>
<td>11:00 AM</td>
<td>Ketta Hill, PT</td>
<td>573.883.9366</td>
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<td></td>
<td>St. Peters Movement Training Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle</td>
<td>Level 2</td>
<td>Tuesday</td>
<td>10:00 AM, 11:00 AM</td>
<td>Rachel Lehman, OT</td>
<td>636.916.9650</td>
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<td></td>
<td>*St. Peters Aquatics St. Charles YMCA, 3900 Shady Springs Ln.</td>
<td>Level 1-2</td>
<td>Thursday</td>
<td>1:45 PM</td>
<td>Alicia Bunn, CTRS</td>
<td>636.896.0999 x21 (registration)</td>
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<td></td>
<td>Town and Country Tremble Clefs Choir Maryville University, 650 Maryville University Dr. Walker Building-Community Room</td>
<td>Thursday</td>
<td>1:30 PM</td>
<td>Megan Moran, MT</td>
<td>636.778.3377 (registration)</td>
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<td></td>
<td>Washington Exercise for Parkinson’s (cycle + strength) Four Rivers YMCA, 400 Grand Avenue</td>
<td>Level 1</td>
<td>Tuesday</td>
<td>1:00 PM</td>
<td>Tim Peters</td>
<td>636.239.5704</td>
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</tbody>
</table>

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

~2 Non-affiliated exercise classes are listed on our website only.
Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list or if you’d rather receive an electronic version.

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

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

SAVE these DATES!

MAY–JUNE
Driving Retirement Workshop Sessions
NEW! Driving Retirement Workshop – Four session program for people with Parkinson’s and their families to help plan for driving retirement.

The workshop will address understanding how Parkinson’s can affect someone’s ability to drive, assessing safety on the road, exploring local transportation options, and creating a personalized plan to maintain independence.

Sessions begin on Fridays, 10:00 AM – 12:00 PM, at the APDA Resource Center beginning 5/31/19

Session 1: 5/31/19, Session 2: 6/7/19, Session 3: 6/14/19, and Session 4: 6/21/19

AUGUST 4
Gotta Go Right Now and Can’t Go At All!
Johanna Hartlein, NP, Washington University Movement Disorders Section, will present tips for dealing with the chronic problems of bladder and bowel (incontinence and constipation) issues in PD. This program will be held at Congregation Shaare Emeth, in the Simcha Center, starting at 2:00 PM.

SEPTEMBER 8
Wendy Suzuki
The Elliot & Mary Ann Stein Speakers Series featuring Wendy Suzuki, NYU neuroscientist and author of Healthy Brain, Happy Life, will address exercise, neuroplasticity, and expanding cognitive reserve. The program will be held at 3:00 PM at Congregation Shaare Emeth, and tickets may be purchased online or by calling the APDA Resource Center starting in June.

OCTOBER 19
Optimism Walk
Logan University
This fun, family-friendly event provides participants with a short walk, vendor booths, raffle, activities for kids, and time to visit and meet others who have Parkinson disease.

NOVEMBER 3
Deep Brain Stimulation (DBS) Treatment in PD
Information and options for the treatment of PD using Deep Brain Stimulation (DBS) with a panel of physicians including neurosurgeons, movement disorder specialists, and individuals who have undergone DBS and can share their personal stories with the audience. This program will be held in the Kehillah Center at Shaare Emeth and will start at 2:30 PM.