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OUR MISSION

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

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

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Midwest Parkinson Congress

Exceeds Expectations!

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:



Rebecca Gilbert, MD, Keynote Address

- 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. A videotape recording will also be available soon. Photos from

the Congress are available for viewing on our website, www.apdaparkinson.org/greaterstlouis



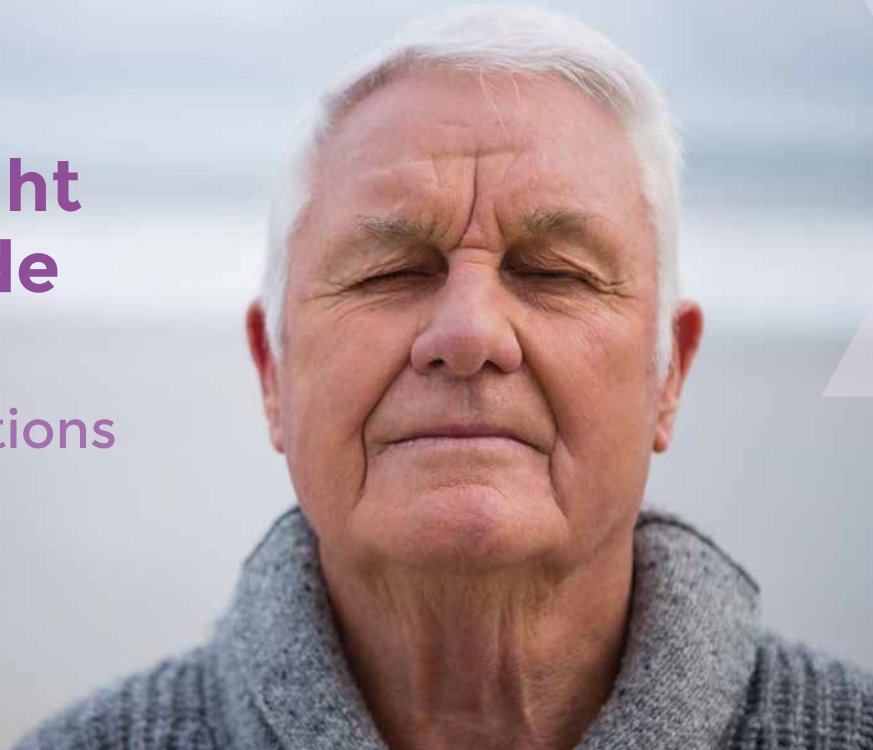
Beth Templin, DPT, HouseFIT, Avery Seidel

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

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

A Primer on Hallucinations and Delusions and How to Manage Them



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.

CONTINUED IN THE NEXT ISSUE

How to Care for Someone who Experiences Hallucinations

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

It is reprinted here with their permission.



Joel Perlmutter, MD



Christine Alsop, JD

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/>. 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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Hospice Care:

High Quality of Care at the End of Life

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



Patrick White MD, HMDC, FACP, FAAHPM, Stokes Family Endowed Chair in Palliative Medicine and Supportive Care, Chief, Division of Palliative Medicine, Department of Internal Medicine, Washington University School of Medicine, Chief Medical Officer, BJC Home Care

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

It can be difficult to broach the subject of hospice with family. There is help available.

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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Ivajeau & Milton Erlich
Terry Friedman
Daniel Grossman
Shirley Heiman
Mr. & Mrs. Ted Kraizer
Amy & Larry Lentin
Dennise & Bill North
Avery Seidel
Jill & Steve Starr
Mr. & Mrs. Gregory Welch
Steven Wicklund
Delphine & Paul Williams
Jana Lewallen
Terri & Dave May
Roland Lindhorst
Gayle Brouk
Barb Lindhorst
Raymond Marcus
Pam & Jerry Brown
John McCormack
Rock Steady Boxing
STL-Crestwood
Dr. Gerald Medoff
Janet & Richard Aach
Academy of Science
of St. Louis
Howard Alster
Marge & Robert Edelman
Amy & Brian Gage

The Gatesworth
 Ronald Goldman
 Joanne & Joel Iskiwitch
 Kimi Kobayashi
 Jane & Tom Mendelson
 Walter O'Donnell
 Simone Picker
 Marcia Sokol-Anderson
 & Frank Anderson
 Jacob Sosna

Louis Merlo
 Cynthia Agnello & Family
 Judy & Louis Clavenna
 Debra & David Crist
 Mr. & Mrs. Dennis Curtis
 Gail & Bob DeGunia
 Endoscopy Department,
 Anderson Hospital
 Kelly & James Feldmann
 Rose Ann & Tom Figliola
 Ellen & Scott Griffith
 Grossman Iron & Steel
 Julia Hillyer
 Amanda Hosner
 Susan & Gary Hyde
 Lisa Jett
 Jessica Merlo
 Patricia & James Merlo
 Carol & Dennis O'Brien
 Susan & Jack Pritchett
 Sharon Rathsam
 Grace Shaw
 Peggy Sheffold
 Cynthia Steiger
 Suzanne & Matthew Steiger
 Robert Williams
 The Young Family

John Mitchell
 Mary Ann Callen
 Julia King
 Rebecca McDermott
 & Denny Donnelly
 Lisa & Kim McMullin
 Susan & Bob Nicholson
 Marilyn & Andrew Presti

**The Brother of
 Dwight Morris**
 Gail & Larry Glenn

Leola Murphy
 James B. Hyde, Jr.

Joseph Nash
 Mr. & Mrs. Don Ross
 Sue & Ron Schowalter

Jim Niehoff
 Judith Beckerle
 & Richard Redel
 Jean Steck Brennan
 Donna & Steve Broderson
 The Springfield Cosgroves
 D&H Trucking
 Mary Fischer
 Warren Hallam
 Betty Hoffman
 Joan & Jary Kivett
 Pat & Paul Mathias
 Mr. & Mrs. Jack Oates
 Sunny & Ray Oberkramer
 Employees of Pro Roller
 Jackie & Dennis Smith
 Mary Steck
 Mr. & Mrs. Charles
 Umphenour
 Lynda Wiens

Seth Otto
 AW Health Care

John W. Patton
 Carolyn & Ron Drudik

Jim Peterson
 Jean Peterson

Royce Powell
 Ruth Elbom, Harlan
 Nissenbaum, Susan,
 Stacy & Scott Rich
 Norma & Carl Fitzwater
 Geri & Steve Hirschtritt
 Sharon & Henry Shaw

Patricia Ann Reed
 Linda Whittemore

Bill Rankey
 Rachel Rankey

Warren Rich
 Mr. & Mrs. David McVey
 Angela & Timothy Weisner
 Lynda Wiens
 Michael Zaitz -
 Affinity Law Group

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 DRS Land Systems
 Karen & Bill McCabe
 Diane & Ed Meier
 Angie & Greg Metzler
 Denise & Mark Wellman
 Julie White
 Ann Wiegers

Sylvan Sandler
 Lisa Ackerman

Dawn Schnur
 Liz & Chuck Burns

Bob Schulte
 Cathy & Earl Adkison
 Kathy & Jim Schweigert
 Tom Siegel

Eric Schwartz
 Linda & Jerry Cohen
 & Mike Donahue

Harriet Wolff Schwartz
 Jeannine & Tony Radin

Ted Schwartz
 Rita Eiseman

Eugene Shepard
 Judy & Jack Lopp

Marty Shrader
 Jean Cody

Norman Snider
 Marrine Grobe
 Sandra & Larry Massey

Mark Snyder
 Ronnie & Allen Brockman

Carl Specking
 Cathy & Earl Adkison
 Connie Hale
 Carol & Matt Hemker
 Lois & Jasper Kermans
 Joanne & Ron Naumer
 Norma & Dale Plank
 Sharon Wein

Michael Steinbaum
 Rita Eiseman

Carolyn Stockton
 Martha & Kevin Hasting

Richard Thompson, Sr.
 Carolyn & Ronald Bulliner
 Nicole & Jim Goetter

Kenneth Weerts, Sr.
 Mary K. Weerts

Janet Yailen
 Debbie & Jeff Dalin
 Barbara & David Furman
 Debbie & Karl Guyer

Joyce Yakel
 Cheryl & Bill Apenbrink
 The Cross Family
 The Eberle Family
 Robin & Kevin Kelly
 Kathy & Kevin Knight
 Mary Koeller
 Mary & Tony Lynn
 Jean Marquart
 Susan & Gary McLean
 Elaine & David Roehrs
 Jeanne Rolfe &
 Mary Ann Scott
 The Wednesday Card
 Players-Becky Drysdale,
 Barbie Kline, Mary Gerst

Dr. Gary Zuckerman
 Fit 'n Fun Exercise Class
 at the Center of Clayton
 Shirley Heiman
 Dr. & Mrs. John Kelly
 Leah Rubin & Jeff Cohen
 Jessica Schwartz
 Nancy & Herbert Seidel
 Carin & Erik Thyssen

Marcia Zuke
 Sandra Muehniek

GENERAL GIFTS

Up to \$99
 Alana & Mark Adkins
 Ellen Albers & Jeff Mitchell
 Lynn & Curt Alferman
 Nancy & Bill Anderson
 Mira Bantcheva
 Jay Bender
 Bill Billings
 Lewis Billingsley
 Denise Bomar
 Leah & James Borden
 Barbara Butchart
 Charlotte & Ron Calhoun
 Dan Carver
 Karen Castanis
 Kathleen & Garry Chaput
 Nancy & Dick Chin
 Convergence Dance
 & Body Center
 Jane Corrigan
 Cris Cosas
 Janis Craig
 Richard Distler
 Mrs. Charles Eckert
 Ernestine Edelmann
 Ellen Farber
 Sheryl & Mike Ferrara
 Marie & Donald Fischer
 Nancy & Tom Freeman
 Terry Friedman
 Patricia Greene
 Mary Ann & Jerry Gunn
 Charles Harris
 Constance Heienickle

Dan Higgins
 Ken Hollenbeck
 Jerie & William Ilch
 Mark Jakiela
 Dawn & Nicolas Kattentidt
 Curtis Kloehn
 Rev. Johnnie Lampkin
 Elizabeth Lester
 Cherng & Kou Li
 Jim Loepker
 Christel Maassen
 Ariel Martin
 Deborah & David Mason
 Nancy McClure
 Theresa McDonough
 Stephen Meyer
 Sharon Miller
 Tom Monahan
 Robert Morgan
 Debra Morrissey
 Carmen Myers
 Donna Nickum
 Mark Osborn
 Marie & David Oughton
 Helen & Austin Peppin
 Louis Peters
 Peter Pisaneschi
 Norma & Dale Plank
 Gwendolyn Portwood
 Joseph Price
 Mary Jo & Harold Rehg
 Jeff Rose
 Judith Schuster
 Sandra Schutte
 Marilyn Scott
 Mary Seaton
 Sue Shumate
 Bill Sorrell
 Michael Sparks
 Perry Sparks
 Sharon & Mel Spiegelglass
 Robert Steele
 John Strebler
 Larry Talken
 Lela & Fred Taussig
 Sheila Teague
 Beverly & Ed Thiele
 Mary Elizabeth
 & James Toebe
 Jane Treadwell
 Nancy & David Trower
 Rebecca & Gary Vosburgh
 Madeline &
 Daniel Walkenbach
 Twila & Cohen Walters
 Marilyn & David Wiethop
 James Witherspoon
 Richard Wizeman
 Georgia Wright
 Lita & William Zschoche
 Vivian Zvibleman

\$100-\$499
 Robert Babione
 Nancy & Robert Baglan
 Joan & Robert Beitel
 Linda Bouchard
 Susan Brandom
 Barbara & Albert Buck
 Jean Cody
 Myra Crandall
 Cecile & Jerry Davis
 Maryellen & Roger Davis
 Janet Forsman

Cathy & Dennis Frey
 Linda Gibbons
 Carol Heddinghaus
 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 McVoy
 Judi & John Nassif
 Alice & Andre Nutis
 Annette Owings
 Roger Peters
 Patricia & Glenn Phillips
 Kathleen Morris
 Susan & John Rothenheber
 Diane & Karl Schoenefeld
 Kathy & Doug Schroeder
 Scott Seddon
 Brenda Shipp
 Cindy & David Smalley
 Edie & Rob Smith

\$500-\$1,999
 Mary Carpenter & Phil Estep
 Amy & Bill Hinderer

ANNUAL GIVING

Up to \$99
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 Constance Dankmyer
 Marie Dealey
 Dienna & James Drew
 Doris Ebersole
 John Jaeger
 Edith Kapfensteiner
 Linda & Bill Kennedy
 Freda Lohr
 Kathleen Overkamp
 Margie & Dewain Reimer
 Laurie, Alan &
 Aliza Dien Yailen

\$100-\$499
 Jo Alessandrini
 Joann & Brian Elliott
 Richard Ellison
 Michelle Gauthier
 Charles Kohlenberger
 Diane & Donald Lange
 Linda & Lewis Miles
 Garry Moeller
 Martha & Tom Monahan
 Marilyn & Ron Oster
 Christy & Bob Pratzel
 Dennis Puricelli
 Mr. & Mrs. Albert Rotskoff
 Mary K. Weerts

\$500-\$1,999
 Joanie & Mark Goldstein
 Margaret Lashley
 Hannah & Herzl Locks
 Stephen Muench
 Jack R. Strosnider, Sr.

\$5,000-\$9,999
 Anne Herron
 Scott Lentin Fund

Connecting Through Art



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.

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).

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.

Time to Start Putting Together Your Teams for the 2019 Optimism Walk

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.”

To learn more and to register for the Greater St. Louis Chapter Optimism Walk, visit <https://www.apdaparkinson.org/get-involved/optimism-walks/> or call 636.778.3377 today!



DIY EVENT

NOVEMBER 2018

TRIVIA NIGHT

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.

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 Girardeau	Cape Girardeau Public Library 711 N Clark Street	4th Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2678
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	11:00 AM	Tricia Creel, 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
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 1125 Madison St.	3rd Friday	1:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Every Monday	3:00 PM	Nancy Dunaway	417.556.8760
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816.861.4700 x56765
Kirkwood	St. Louis	First Presbyterian Church of Kirkwood 100 E. Adams Ave., Room 009, Lower Level	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW Patty Waller	314.286.2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place, Lower level	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314.372.2369
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps Health, 1000 W. 10th St. Private Dining Rm #1	4th Thursday Nov mtg 3rd Thurs	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	Jody Peterson, OTA Jessica Womack	636.724.4357
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Teddy Ross	618.210.7371
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283
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.

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

CITY	MEETING SITE	LEVEL	DAY OF MEETING	TIME	LEADER(S)	PHONE
Breese	Exercise for Parkinson's (cycle + strength) Clinton County YMCA, 14160 Jamestown Road	Level 1	Monday Wednesday	2:00 PM	Jack Swank Vicky White	618.526.5628 (registration)
Carlinville	Movement Training Carlinville Area Hospital, Medical Office Building, Community Room, 20613 N. Broad	Level 2	Thursday	10:00 AM	Amy Murphy, PT	217.854.3141 x377
Edwardsville	Movement Training Edwardsville YMCA, 1200 Esic Drive	All levels	Tuesday & Friday	11:00 AM starts June 4, 2019	Ann McLean	618.656.0436 (registration)
*Highland	Exercise For Parkinson's (cycle + strength) Korte Recreation Center, 1 Nagel	Level 2	Monday Wednesday	1:00 PM	Jinee McDonnell- Stewart Ginger Kabureck	618.651.1386 (registration)
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 Wednesday Thursday	10:00 AM (W) 1:30 PM (Tu, Th)	Eve Fischberg, OT	217.494.4961

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



Missouri Exercise Classes

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

CITY	MEETING SITE	LEVEL	DAY OF MEETING	TIME	LEADER(S)	PHONE
*Brentwood	Tango Convergence Dance and Body Center, 8044 Manchester 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 PM 11:30 AM	Tricia Creel, PT	636.778.3377
Chesterfield	Tai Chi 1415 Elbridge Payne, Ste. 163	Level 1 Level 2 Level 1	Tuesday Wednesday Friday	11:15 AM 10:00 AM 10:15 & 11:30 AM	Craig Miller	636.778.3377
*Chesterfield	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	Wednesday Friday	1:00 PM 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	Roll With the Punches The J's Stoenberg Family Complex, 2 Millstone Campus Dr.	Level 3	Tuesday Thursday	1:00 PM	Joe Ryan	314.442.3452 (registration)
Florissant	Movement Training Garden Villas North, 4505 Parker Rd.	Level 1	Thursday	10:00 AM	Nancy Robb	314.869.5296
Ladue	Tremble Clefs Choir Salem United Methodist, 1200 S. Lindbergh Blvd., Lower Level Choir Room		Saturday	1:30 PM	Linda McNair, MT-BC	636.778.3377 (registration)
Maryland Heights	Exercise for Parkinson's (cycle + strength) Edward Jones YMCA, 12521 Marine Ave	Level 1-2	Tuesday	12:00 PM	Martin Caupp	314.439.9622 (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	Colleen Bock, PTA	636.233.2813
South St. Louis County	Exercise for Parkinson's (cycle + strength) South County YMCA, 12736 Southfork Road	Level 1-2	Friday	10:30 AM	Diane Summers	314.849.9622 (registration)
South St. Louis County	Fit 'n Fun Garden Villas South, 13457 Tesson Ferry Rd.	Level 1	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
South St. Louis County	Movement Training Friendship Village Sunset Hills, 12563 Village Circle Drive	Level 2	Friday	10:00 AM	Marina Clements, PT	636.778.3377
*South St. Louis County	Circuit Training HouseFit, 3809 Lemay Ferry Road	Level 2-3	Tuesday & Thursday	11:00 AM	Marina Clements, PT	314.339.7430 (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	Rachel Lehman, OT	636.916.9650
*St. Peters	Aquatics St. Charles YMCA, 3900 Shady Springs Ln.	Level 1-2	Thursday	1:45 PM	Alicia Bunn, CTRS	636.896.0999 x21 (registration)
Town and Country	Tremble Clefs Choir Maryville University, 650 Maryville University Dr. Walker Building-Community Room		Thursday	1:30 PM	Megan Moran, MT	636.778.3377 (registration)
Washington	Exercise for Parkinson's (cycle + strength) Four Rivers YMCA, 400 Grand Avenue	Level 1	Tuesday Friday	1:00 PM	Tim Peters	636.239.5704 (registration)

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

-2Non-affiliated exercise classes are listed on our website only.

Photo by Aquachara via Unsplash

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!

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION

GREATER ST. LOUIS CHAPTER

Strength in optimism. Hope in progress.

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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.

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.

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.

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.