

### MISSION

Our mission is to enhance the quality of life for people with Parkinson’s disease, their families, and caregivers in our communities throughout Missouri and southern Illinois, and to provide funding for ongoing Parkinson’s disease research.

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**NEWSLETTER DISCLAIMER**  
 “The information and reference material contained herein concerning research being done in the field of Parkinson’s 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.”

## PARK PLACE

For an avid Monopoly player, those two words must conjure up the most expensive real estate on the game board, short of Boardwalk. But for a Parkinson patient, rather than suggest a financial worth, those two words should suggest an even more valuable site. My husband, Karl, suggested we add an “e,” PARKE PLACE, but I don’t particularly like the reference frequently used by patients themselves, Parkie, so I would never add an “e,” silent or otherwise.

Prior to the Greater St. Louis APDA Board of Directors conducting an extensive property search, under the direction of 40-year commercial real estate veteran and new Board member, John Basilico, and just a week before the final vote, the Parkinson Research Foundation, located in Sarasota, FL, sent out an e-blast announcing PARKINSON PLACE

coming soon. “Evidence-based programs designed to empower, educate, and energize patients and caregivers through every stage of the disease process” will be available, and membership is free.

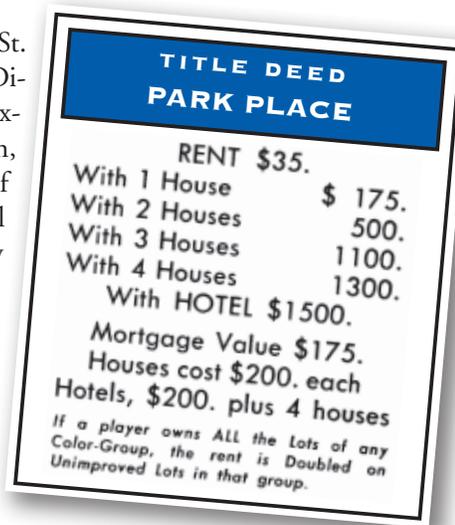
Our St. Louis PARK PLACE is located at 1415 Elbridge Payne, Suite 150, in Chesterfield, accessible through the main doors and, will also provide a “new and unique destination spot,” all under one roof. We will have group participation programs including the Chesterfield support group, For Caregivers Only support group, chair-exercise program, LOUD Crowd-Voice Aerobics, Wellness Course, Tai Chi, Adult Children of Parents with Parkinson’s support group, PD101, and Caregiving 101. It will also be

home to our support group facilitator training classes, training for agency personnel caring for Parkinson patients, committee meetings, fundraising activities, auction basket assembly, and other special events. Members of the APDA Information and Referral Center staff, Board members, along with other volunteers, will staff the center Monday through Friday, 7:30 a.m. – 4:00 p.m. and be available to answer questions, assist you in the resource library, or on an internet search.

We will still have a presence at Washington University School of Medicine, Movement Disorders Section, our host institution. Webinars and archived PEP meetings will be available for viewing during office hours or by appointment. Our resource library room will contain many recent publications, CDs, DVDs, books, community resources. The majority of our large equipment lending loan closet will still be located off-site; however, smaller, adaptive equipment will be available

at no charge from this location. Our large lecture programs will continue to be held in venues which can accommodate the 500 people who regularly attend these quarterly presentations.

Recalling the words from the movie, “Field of Dreams,” if you build it they will come, I encourage you to drop by and visit. More information will be available on our website, [www.stlapda.org](http://www.stlapda.org). PARK PLACE – a new and unique destination for those impacted by this disease. Patients, families, care providers, professionals, and others interested in learning more about Parkinson disease and supporting our mission are all invited to stop in. Looking forward to your visit! For further information, please contact us at 314-362-3299. ■



**APDA  
GREATER ST. LOUIS CHAPTER**

Deborah Dalin Guyer, MA, Coordinator  
guyerd@neuro.wustl.edu  
Elaine Dreher, Program Coordinator  
drehere@neuro.wustl.edu  
Christine Karsh, Event Planner, Development  
karshc@neuro.wustl.edu

**ST. LOUIS CHAPTER  
COMMUNITY RESOURCE CENTER**

1415 Elbridge Payne, Suite 150  
Chesterfield, MO 63017  
Office Hours:  
Monday–Friday 7:30 AM–4:00 PM  
314-362-3299 • 314-747-1601 (fax)

**APDA INFORMATION & REFERRAL CENTER**

Campus Box 8111 • 660 S. Euclid  
St. Louis, MO 63110  
www.stlapda.org

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**NATIONAL AFFILIATION**

APDA • 135 Parkinson Ave.  
Staten Island, NY 10305  
800-223-2732

**EDITOR**

Deborah D. Guyer

**CONTRIBUTING EDITORS**

Linda Clark  
Elaine Dreher  
Betty Hayward



# WHEN THE PARKINSON PATIENT NEEDS SURGERY

Michael Rezak, M.D., Ph.D., Director, Movement Disorders Center, Neurosciences Center, Central DuPage Hospital

Recently, I have received a number of inquiries regarding PD patients who have scheduled surgical procedures and some who have required emergency surgery. Special consideration must be given to the PD patient that requires any type of surgical intervention. The physical and emotional stress that surgical procedures can impose impacts PD management. Foreknowledge of potential problems may preclude their development.

In the following paragraphs, I have chosen a question and answer format using actual questions posed by patients and their families, as well as by physicians. The selected questions will also address potential complications seen in PD patients that undergo any surgical procedure.

**Q. When should PD medications be discontinued before surgery, and how soon can they be restarted after surgery?**

**A.** PD medications should be continued as close to the surgical procedure as possible. This is typically about three hours before the procedure, allowing the patient to remain as comfortable as possible. There is no longer a need

to discontinue MAO-B inhibitors (particularly Azilect®) before surgery as this class of medicine has been shown to be safe with anesthetics and most pain medicines. The only contraindicated pain medicines are meperidine and tramadol. To date, there have been no negative interactions documented with MAO-B inhibitors and pain medicines. Following surgery, PD medications should be restarted as soon as the patient can safely swallow. Unfortunately, there are very limited number of effective dopaminergic drugs that can be administered by routes other than orally. The exceptions to this are Apokyn®, Cogentin®, and Zelapar®. Apokyn® is an injectable dopamine agonist and is the most efficacious of the previously mentioned drugs, but must be used with caution in the post-operative period (especially if an effective dose has not been established pre-operatively) and only if an anti-emetic is used concurrently. In most cases, if a patient is recovering from gastrointestinal surgery that requires l-dopa, I recommend giving medications via nasogastric tube with suction off and the tube clamped

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## BOARD BRIEFS

**Brook Dubman**, a Director on the APDA Board, regretfully resigned his position in late June due to increasing business demands at Carol House Furniture, serving on other boards, and having a need for time with his wonderful family who share Brook with so many charitable organizations. He had served as a Director on our Board for over 16 years. Brook has assured us that he will continue to lend his name to the Nat



Dubman Memorial Golf Tournament and his financial support as a sponsor for our worthy cause. ■

## WHEN THE PARKINSON PATIENT NEEDS SURGERY

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for 30-45 minutes after the medicine is delivered to allow for absorption. In this type of situation, Apokyn® could also be used here, either as the primary medication or as an adjunct. Zelapar® is an MAO-B inhibitor that is uniquely absorbed through the oral mucosa thereby bypassing the gastrointestinal track.

**Q.** *What are the dangers in delaying restarting dopaminergic medications after surgery?*

**A.** The post-operative period can be difficult under any circumstances; however, with the additional burden that PD imposes, resumption of optimal motor function as soon as possible is of paramount importance in order to minimize any of the potential problems.

First, delay in reinitiating PD medications can compromise motor function including those of respiratory (breathing) and pharyngeal (swallowing) muscles. Poor respiratory muscle function can lead to impaired coughing and restricted movement of the respiratory muscles (limiting deep breaths). Additionally, swallowing problems can develop or worsen without PD meds, thus increasing the risk of aspiration. These problems, taken together with the decreased ability to move about, make the common post-operative complication of pneumonia much more likely.

Second, the rigidity, bradykinesia, and resultant decrease in movement brought about by the lack of PD medications increase the post-operative risk of developing blood clots in the legs (deep venous thrombosis (DVT)) related to sluggish blood flow. In some cases, these blood clots can travel to the lungs causing a life threatening pulmonary embolus. Mobilization is therefore a major post-operative goal after any surgery and not being on PD medications increases risks and delays optimal rehabilitation.

Finally, a rare, but potentially life threatening condition known as neuroleptic malignant syndrome (NMS) must be a concern whenever dopaminergic drugs are stopped abruptly. In NMS, mental status changes, rigidity, tremor, fever, and autonomic instability can have serious consequences. If recognized early, treatment can be lifesaving.

**Q.** *Should a PD patient do anything special pre-operatively to maximize the possibility of a good recovery?*

**A.** Of course, obtaining general medical clearance prior to surgery is the standard of care. This allows for correction of any problems before the surgical procedure. Additionally, I recommend that some patients undergo a formal video



fluoroscopic swallowing evaluation, as well as obtain pulmonary function tests so that baseline measurements can be obtained and appropriate planning for potential post-operative difficulties be instituted. Also, it is important to stop any prescription or over-the-counter medications that increase bleeding such as Coumadin®, Plavix®, aspirin, vitamin E, Gingko Biloba, etc. Maintaining good hydration and appropriate nutritional status, as well as optimizing overall physical conditioning, will maximize the potential for a good and smooth recovery.

**Q.** *What medications should be avoided following surgery?*

**A.** Needless to say, all drugs that block dopaminergic transmission need to be avoided. Post-operative nausea and vomiting are extremely common, and

medications such as Reglan®, Compazine®, and Phenergan® are considered first-line medications to treat this problem. Because of their interference with dopamine transmission, they will certainly worsen PD symptoms and should therefore be avoided. If treatment for nausea and vomiting is needed for the PD patient, the drug of choice is Zofran® or alternatively Tigan®. These drugs do not interfere with dopamine function and can be given intravenously or orally.

Post-operative confusion and agitation are another situation where dopamine-blocking agents are often employed. The older neuroleptics such as Haldol® and closely-related drugs should be avoided. The newer, so-called, “atypical neuroleptics” such as Abilify®, Risperdal® and Zyprexa® may also have a deleterious effect on motor function in PD patients. The drugs of choice for the treatment of post-operative delirium are Seroquel® and Clozaril®. They are effective and have minor impact on PD symptoms. Seroquel® is easy to use and is considered the best option for the PD patient.

In general, when the PD patient needs hospitalization, multiple copies of the medication schedule with exact times of administration should be supplied to all of the physicians and nurses involved in their care. Upon arrival at the hospital, a discussion of PD and the importance of proper medication administration should take place with the staff. If possible, an advocate (e.g., spouse, child, caregiver) should be assigned with the task of assuring that medications are given on time and in the correct doses.

In closing, I hope that through these questions and answers I have emphasized that “micro-managing” the PD patient before, during, and after a surgical procedure decreases the risk of complications and increases the likelihood of a good and full recovery. As always, it is important for the PD patient to be his or her advocate in assuring that all of the details are in order. ■

# FROM HOSPITAL TO HOME – TRANSITIONS OF CARE

Althea West, MA, LTCP, CMC

I received a call early one morning that one of my clients was “unresponsive” upon waking. The care provider asked if she should call 911, and based on the circumstances, we decided it was appropriate to get emergency assistance. My client had mild dementia due to Parkinson’s, as well as insulin-dependent diabetes and a pacemaker. It was discovered he had a severe infection (from some recent dental work), and after several days in the hospital, the discharge planner suggested he be sent to a skilled nursing facility for rehabilitation.

The skilled nursing facility was lovely and had the services he needed. However, because of my client’s special circumstances, he needed a higher level of attention than the staffing ratio allowed. Within about four days, he was back in the hospital to get treatment for inflammation in his legs (and more intravenous antibiotics to treat his recurring infection). After several more days in the hospital, the discharge planner again suggested my client be sent back to the skilled nursing facility. At that point I decided that a safe, familiar environment with one-to-one assistance would be a better choice. So, we arranged for my client to go home with the support of a multi-disciplinary care team (visiting nurse, physical therapist, non-medical care provider, and care management).

Professionals have been talking for quite some time about how to protect patients during their transition of care from one care setting to another (i.e., from the hospital to a rehab facility, from a rehab facility to home) in order to stop the “revolving door” of multiple hospital readmissions. As you might imagine, there are risks of:

- “Poly-pharmacy” (too many prescription medications, too many changes and instructions, or too many doctors who have prescribed medications)
- Non-compliance with prescribed treatments

- Inadequate staffing support for those who are frail and prone to infections or those who have confusion or short-term memory loss
- Poor communication and misunderstandings about warning signs and adverse effects

“Patients face significant challenges when moving from one care setting to another within our fragmented health care system. As currently structured, the U.S. health care system does not meet the needs of many patients during transitions between health care settings. The system’s problems have culminated in medical errors and gross mismatches of health care resources to needs” (MR Chassin, JAMA, 1998).

Several studies recently have shown that lack of knowledge about one’s health, the lack of appropriate follow-up, and miscommunication among service providers lead to serious consequences following hospital discharge. The common denominator in all the instances of care is the patient, who with sufficient knowledge and tools can proactively start the conversation and interaction between providers.

There is a research-based hospital to home care transition program designed to reduce hospital readmissions, and it is most helpful to those patients who have chronic care needs. There is a wealth of information on the consumer website [www.hospitaltohomecare.com](http://www.hospitaltohomecare.com) that is designed for patients and their families to gain access to how the discharge-planning system works in hospitals and to empower patients to know they have a choice as to where they receive care once they are released from the hospital.

The following tips can help patients and their families plan effectively for discharge and recovery:

- Understand your care options prior to discharge. If you prefer to recover at home, make your

## AWARE IN CARE

The National Parkinson Foundation (NPF) recently launched a campaign called **Aware in Care** to draw attention to the fact that PD patients often do not get good quality care when they are hospitalized.

Unfortunately, their hospital stays are usually met with complications because of medication timing and other critical issues. These complications often prolong hospital stays and cause serious setbacks. An **Aware in Care** kit, available from the NPF, includes tools and information that will help people with Parkinson’s and their families plan for their next hospital stay.

The kit includes:

- Aware in Care** Bag
- Hospital Action Plan
- Parkinson Disease ID Bracelet
- Medical Alert Card
- Medication Form
- PD Fact Sheet
- I Have Parkinson Reminder Slips
- Thank You Card for the hospital staff
- Magnet which says, “I have Parkinson’s and I need my medications on time, every time,” (a visual reminder of the importance of medication timing for people with Parkinson).

To obtain a free **Aware in Care** kit, call NPF at 1-800-473-4636. A kit is available for viewing at the APDA Information & Referral Center (WUSM) and at the APDA Community Resource Center in Chesterfield. ■

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## FROM HOSPITAL TO HOME

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feelings known to the discharge team.

- Write a list of your prescription drugs, over-the-counter drugs, supplements, and vitamins, including your regular dosage and medication times. Make sure the medical team is aware of any drugs you were taking prior to hospitalization to prevent unintended complications.
- Obtain a list of home-medical equipment, such as a walker or hospital bed, to facilitate your recovery at home. You should plan to acquire and install this equipment prior to discharge.
- If you require regular therapy, testing, or medical checkups, write down a schedule of your appointments, including contact information for each.
- Ask the staff to demonstrate any



tasks that require special skills, such as changing a bandage.

- Ask your discharge team about common problems for patients with your health condition, what you can do to reduce your risk, and what you should do in the event of emergency.

- Understand your physical limitations and areas where you need support. For example, you may have mobility issues after discharge that will prevent you from safely walking around the house or running errands.
- Ask to speak with a social worker if you have concerns about coping with your illness. A social worker can provide you and your family with information on managing your illness, support groups, and other resources.
- Request written discharge instructions and a summary of your current health status. Bring this information and your medication list with you to any follow-up medical appointments.

For a “Discharge Planning Checklist,” “Home Care Agency Comparison Checklist,” or more information about multi-disciplinary care teams, please contact Althea West by calling 636-734-6566 or emailing [Althea.west@hcamo.com](mailto:Althea.west@hcamo.com). ■

## FORCED EXERCISE – USING A THERACYCLE

Jim and Pam Miller, Springfield, IL

Under the *Recent News* section in the St. Louis APDA website, I learned about the use of forced exercise to help relieve the symptoms of Parkinson disease (PD) discovered during a bike ride across Iowa. The article, “What Parkinson’s Teaches Us About the Brain,” reported that Dr. Jay L. Alberts entered the ride with a partner and a tandem bike. His partner, a woman with PD, rode the rear position while Dr. Alberts rode the front position. After the first day’s ride, the woman, whose handwriting was characteristically minuscule and illegible, was signing her name in cursive that was legible and beautiful. Improved gait and balance were also observed.

Dr. Alberts has since used stationary tandem bikes and experienced rid-

ers as pace setters to conduct his own research. He reported a 35% improvement in symptoms over other forms of exercise. Realizing that tandem bike riding was not feasible for every Parkinson individual, Dr. Alberts sought a motorized stationary bike. A company in the Boston area, The Exercycle Company, produced such a product, a Theracycle. Incidentally, they also make a model for wheelchair pedaling.

With this knowledge, I contacted the company at [www.Theracycle.com](http://www.Theracycle.com) and requested further information. A packet came in the mail, and a representative soon telephoned. No one in my immediate community owned a Theracycle, but I was provided references. I chose not to call them, but my wife and I did stay in touch with the representative

who was able to answer all our concerns.

Admittedly, I had not exercised regularly for some years, except for some golf in the summer months. However, this seemed like something I could do. My wife thought perhaps the Theracycle might even adjust to her smaller size, and it did. Then we had to decide in what 2’ x 4’ space the Theracycle would fit. A corner of the bedroom was the best spot.

In less than two weeks, UPS delivered the Theracycle in one box to the front door. The unit weighed 243 pounds. Some assembly was required, but the tools needed and good directions were enclosed. I summoned some younger muscles to assist me.

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## THERACYCLE

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Riding began the day of arrival, December 9, 2011, at the leisurely pace of 8 MPH for 15 minutes (2 miles). Riding early in the morning, it was fortunate that the motor was quiet and did not awaken my wife. Each week I increased one of the variables until I achieved my current level: 13 MPH for 25 minutes and 14 MPH (92 RPM) for 20 minutes (10.5 miles).

After about four weeks, with the exception of generally feeling better, I had not noticed a great improvement in PD symptoms. However, my wife thought that I was much more alert and communicated more because I was less drowsy. Early on Tuesday morning, January 12, 2012, I WALKED (not shuffled) down the hall to the kitchen, unlike previous mornings! This was before I took my morning Parkinson meds. My wife has added that I seem to have more energy all the time, although we are sure the unseasonably warm winter days have had some influence.

Is the Theracycle expensive? YES. Does it deliver results? It does for me. Do I recommend the Theracycle? Yes, but only you can make a decision to invest in one.

Jim's wife, Pam, inquired about Jim's handwriting, since a change in handwriting was something that was noted

immediately with the tandem-riding experiment. Today, Jim finished his ride after breakfast and Pam asked him to work on the daily crossword puzzle (his "must do" morning routine). It was when Pam was unsure of her answer and wrote micro letters in the boxes that she saw that Jim's printing in the other boxes was now legible and larger in size. Before, his D's looked like O's and all the letters were not easily recognized.



Will improvement last? Usually the benefit of exercise ceases if the practice stops. On Thursday, March 29, this year, we flew to California for a short visit with our son and his family. Jim's exercise routine would change as did the time zone. Jim experienced changes

in disposition, drowsiness, and appetite. When Jim got up early on Friday to ride the exercise bike in the hotel fitness room, he was energized again. However, he noticed that he could not keep up his usual pace because this bike was powered by his legs instead of the bike motor. The greater resistance caused him to shorten the workout pace and length of time in the exercise room.

Monday, April 2, was a travel day. Airline personnel saw our APDA backpack and asked if we would like to have help boarding, assuring us that it was not a problem and that they certainly did not want Jim to fall. I think Jim wore his Parkinson face that early morning. His arm swung out to the side of his body, making him appear off balance; however, he did not shuffle his feet. Tuesday was a very busy catching-up day for both of us at home. But on Wednesday, Jim was back in the groove – riding his bike before breakfast at his same pace. April 9th marked the four-month anniversary of Theracycling for Jim. Except for a slight lapse when traveling for five days, his PD symptom improvements remain and his blood pressure is perfect.

Pam adds, "This was the right decision for us because I have never had to ask or remind Jim to exercise. He has developed a healthy, new habit on his own. It's great to see him spending less time mourning his old life and more time embracing the present." ■

## USEFUL LINKS

**Orange County Parkinson's Wellness Conference** is now archived and available for viewing at your convenience. You can see and hear this archived event right on your desktop. The only software you need is your standard Web browser. To begin the login process, simply click on the link below:

<http://event.netbriefings.com/event/young-parkinsons/Archives/wellness201206/>

Presented by:

Monique Giroux, MD  
Giselle Petzinger, MD  
Michael Rezak, MD, PhD  
Patrick LoSasso, CSCS  
Jeff Bronstein, MD, PhD

Note that other webinars have been archived on the **National APDA Young-Onset** website. This exciting video and audio library captures presentations from many of the experts on Parkinson's disease:

<http://www.youngparkinsons.org/how-we-can-help/webcasts-and-podcasts>

For those of you seeking ways to track your Parkinson symptoms, Julie Sacks, Director of the APDA National Young-Onset Center has provided useful links: **Parkinson's Well-Being Map**. This pharmaceutical company-based tool is available for people to print or complete online (<http://www.parkinsons-voices.eu/well-being-map/uk>). Since it comes out of the UK,

some of the medications listed are not available or commonly used here in the U.S.

There is also another site, **Patients Like Me** (<http://www.patientslikeme.com/user/signup?simple=false>). This project is primarily about aggregating symptom data (which may or may not be reliable-somewhat controversial). However, in the process of gathering that information, it allows patients to create and update symptom profiles over time.

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# DRIVING SAFELY WITH PARKINSON'S DISEASE

Peggy P. Barco, MS, BSW, OTR/L, Driving Rehabilitation Specialist, Program in Occupational Therapy, Washington University Medical Center in St. Louis, and

David Carr, MD, Professor of Medicine and Neurology and Clinical Director for the Division of Geriatrics and Nutritional Science, Washington University Medical Center in St. Louis, Medical Director of the Rehabilitation Institute of St. Louis

It is now well known that Parkinson's Disease (PD) is not strictly a disease of the elderly – it can impact young and middle-age adults as well. For all age groups, driving is one of those important functional activities that allow us independence and the ability to stay connected in the community. Driving, while very important to one's independence, is also a public-safety issue – especially when a medical condition exists. Being aware of the changes that can occur with various medical conditions, how these changes can impact driving safety, and using good judgment regarding one's own driving ability are important in determining who is fit behind the wheel.

PD is commonly known as a disease that affects movement and motor function. It is widely recognized that in addition to the motor symptoms of PD, there can also be vision, cognitive, and perceptual changes – especially as the disease progresses. The non-motor symptoms that are most common in PD include reduction in contrast sensitivity in vision, difficulties in proprioception, and difficulties with cognitive functioning. All of these non-motor areas have the potential to greatly decrease driving safety in the following ways:

## 1. Decreased contrast sensitivity:

Limited contrast sensitivity affects the ability of an individual with PD to detect visual stimuli in low contrast environments – such as pedestrians in crosswalks on a dark or foggy day. Results of a recent study confirmed that drivers in low contrast conditions with PD displayed less control over their vehicle, had slower responses to hazards, and committed more safety errors than those without PD.

**2. Decreased proprioception:** Proprioception refers to the sense of knowing where one's body in space is and can decline as part of normal aging as well as with PD. While evidence with driving is lacking in this specific area, difficulty with positioning the foot correctly on the gas or brake pedal could be a hazard with decreased proprioception.

**3. Difficulties with cognitive functioning:** Evidence is showing that cognitive changes do occur as PD progresses – and these changes can

the cognitive and perceptual changes appear to be more related to driving safety than the motor symptoms. Being aware of the changes in these cognitive abilities is a positive indicator in remaining a safe driver. For example, if an individual is aware of the cognitive changes, he or she might be more likely to adapt their driving accordingly, such as not driving in low light conditions, driving only in familiar areas and during less traffic conditions. On the other hand, if a driver with PD is not aware of the cognitive changes that were occurring, he or she would continue to drive in demanding conditions likely beyond his or her current abilities.



include decreased attention, memory, problem solving, planning, visuospatial abilities, and decision making (e.g., executive function). Reports from driving studies are indicating that individuals with PD (especially those with cognitive changes) have been found to be less safe drivers – resulting in more driving errors during driving studies.

While many persons with PD (especially those in the early stages) remain safe drivers, it is very important to be aware of the possible changes that can occur as the disease progresses. Especially in relationship to driving and PD,

difficulties maintaining good lane positioning, delayed responses to traffic lights or planning for what lane to get into, difficulty deciding when it is safe to make a turn, relying on non-drivers in the car to help with decision making, and getting lost while driving.

If you, your family member, or physician are concerned about your driving safety, it is advisable to seek a driving assessment which is provided by an occupational therapist driving specialist. These assessments usually take a few hours and include in-depth clinical testing of vision, sensory, motor, and cognitive functions. In addition, the

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# MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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, call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	1:30 PM	Gayle Truesdell	636-923-2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street Oscar Hirsch Room	<b>3rd Monday</b>	6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Satellite Resource Center 1415 Elbridge Payne, <b>Suite 150</b>	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton Doris Heuer	573-964-6534 573-434-4569 573-999-2106
Creve Coeur	St. Louis	For Caregivers Only <b>APDA Community Resource Center</b> <b>1415 Elbridge Payne, Suite 150</b>	2nd Monday	11:00 AM	Dee Jay Hubbard, PhD	314-362-3299
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	<b>Britt-Marie Schiller,</b> <b>PhD</b> Rich Hofmann	<b>314-754-3256</b> 314-369-2624
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Melissa McGuire Nancy Robb	314-355-6100 314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Mondays	2:00 PM	Nancy Dunaway	417-623-5560
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW	314-286-2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy Dalton	573-964-6534 573-434-4569

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## DRIVING SAFELY WITH PD

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assessments involve an *on-road* driving assessment to judge how well an individual's driving ability is in real traffic conditions. These on-road assessments are done in a driving evaluation car (with a passenger side brake for safety). The road assessment usually begins in a parking lot and progresses to higher

levels of traffic. The on-road driving assessment looks at how well the individual manages the car in traffic, visually attends to and scans the surroundings, maintains good lane positioning, follows the rules of the roads, yields to oncoming vehicles, and plans and makes everyday driving decisions. Once both the clinical and on-road driving assessment are completed, the occupational therapist can provide recommendations

back to the individual, family, and physician regarding driving safety.

For further information regarding driving assessments and any current research studies regarding driving abilities and medical impairment that you might be eligible to participate in through Washington University School of Medicine, please call: **DRIVING Connections at The Rehabilitation Institute of St. Louis, 314-658-3846.** ■

# MISSOURI SUPPORT GROUP CALENDAR

*continued from previous page*

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
Springfield	Greene	Park Crest Baptist Church 816 W. Republic Road	Last Thursday	11:00 AM	Kay Meyer	417-350-1665
St. Peters	St. Charles	Spencer Road Library 427 Spencer Road, Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Griffard, RN	573-543-2162
St. Louis	St. Louis	Pre/Post-DBS Sunrise on Clayton Senior Living 7920 Clayton Rd.	3rd Thursday	1:00 PM	Steve Balven Stan & Donna Wilensky	314-249-8812 314-997-5114
Washington	Franklin	<b>Washington Public Library</b> <b>410 Lafayette Avenue</b>	2nd Monday	6:30 PM	Carol Weber	314-713-4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036



# ILLINOIS SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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, call the APDA Information & Referral Center or the facilitator, Information that has changed since the last **LINK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Jodi Gardner	618-234-4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, M.D.	618-549-7507
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	Kathy Broaddus	217-820-3096
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Marilynn Kozyak Jeanette Kowalski	618-288-3508 618-288-9843
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Mattoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217-268-4428
McLeansboro	Hamilton	Heritage Woods - Fox Meadows 605 S. Marshall Ave., Dining Room	1st Wednesday	1:00 PM	Paula K. Mason	618-643-3868
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr. <a href="http://www.parkinsonssupportcentralill.org">www.parkinsonssupportcentralill.org</a>	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088



# EXERCISE CLASSES

Our Exercise Classes meet once a week or otherwise as noted.

Information that has changed since the last **LiNK** appears in **bold face**.

Attend one class per week at no charge, or, for \$20/month, attend as many classes as you want.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Aerobics Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
Clayton	St. Louis	Tango Dance Class* The Center of Clayton 50 Gay Avenue	<b>Friday starting Aug. 31</b>	3:00 PM	Gammon Earhart, PhD, PT	314-286-1425
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	11:00 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	Gardenview Chesterfield 1025 Chesterfield Pointe Parkway	Thursday	2:30 PM	<b>Faye Bienstock, PT</b>	636-537-3333 ext. 204
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	<b>Summer session July 9-Sept. 14 Fall session Oct. 1-Dec. 7</b>	2:00 PM	Brenda Neumann	636-896-0999 ext. 21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Monday	2:00 PM	Nancy Dunaway	417-623-5560
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314-289-4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Ste. 117	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, COTA	636-916-9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	<b>Summer session July 9-Sept. 14 Fall session Oct. 1-Dec. 7</b>	2:00 PM	Brenda Neumann	636-896-0999 ext. 21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534

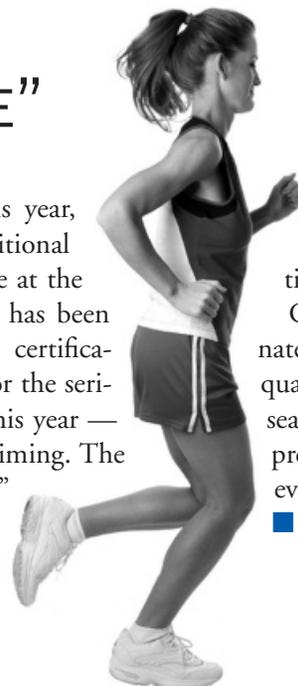
\* **MUST CALL TO ENROLL**

## 7TH ANNUAL "HULL OF A RACE"

The Mark Twain Area Parkinson Support Group's first 5K race was held in August of 2006. Over the six years of this race, more than \$30,000 has been raised and contributed to the National APDA for researching the cure for Parkinson's. The Support Group will hold the 2012 race on Saturday, August 18, in Downtown Park, Hull, Illinois. Registration starts at 7:00 a.m. for the 8:00 a.m. event, but you may pre-register for a reduced fee.

Significant improvements have been

made to the race. This year, there will be an additional timer for runners to see at the finish line; a 10K race has been added; there is course certification for both courses for the serious participants; and this year — chips will be used for timing. The half-mile "Fun Run" for children under 12 has been a consistent attraction and completes the run at the



conclusion of the other two races. There were over 200 participants in the race last year.

Contributions raised will be donated to the APDA, National Headquarters, Staten Island, NY, for research. For more information, or to pre-register online, please visit the event website: [www.hullofarace.com](http://www.hullofarace.com).

# TRIBUTES & DONATIONS

Tributes are a wonderful way to acknowledge the memory of a beloved person as well as honor those who mean so much to you. Tribute envelopes can be obtained from the Center 314-362-3299 or made directly on the St. Louis APDA website, [www.stlapda.org](http://www.stlapda.org).

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*The speedy recovery of Sid Axelbaum*  
Fred & Joy Levin

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*The birthday of John Basilio*  
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*continued on next page*

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*continued from  
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# FORE-TEENTH GOLF TOURNAMENT ANOTHER GREAT SUCCESS!



**W**e were very privileged to have John Mozeliak, GM of the St. Louis Cardinals, serve as our Honorary Chairperson again this year. You probably heard Dan McLaughlin and Mo discussing his involvement with this tournament and his very personal connection to Parkinson disease on Fox Sports Midwest and the St. Louis Cardinals radio network. No matter how you slice it, our 14<sup>th</sup> annual Nat Dubman Memorial Golf Classic was a smashing success, and we managed to dodge the rain and experience one of our gorgeous spring days on May 21st at beautiful Lake Forest Country Club. Following days of 100+ temperatures and drought, it is hard to remember our beautiful spring tournament!

Our success was due in large part to our loyal sponsors, many who support us year after year: **MAJOR** level sponsors: Benton Homebuilders Community Partnership and Carol House Furniture; **GOLF CART** sponsor: The Moneta Group Charitable Foundation; **COCKTAIL RECEPTION** sponsor: Steve and Lynn Hurster; **BREAKFAST** sponsor: Largo International; **BEVERAGE CART** sponsors: Catnapper, Jackson Furniture, Pulaski Furniture; **DRIVING RANGE** sponsor: Montage Furniture Services; and **HOLE** sponsors: American Drew/Lea & Hammary, A.R.T. Furniture, Don Carlson, The Commerce Trust Company, Continuum, Cooperative Home Care, Larry & Sonya Davis, The Delmar Gardens Family, Flexsteel, Grey Eagle Distributors, Guarantee Electrical, Keith & Cindi Guller, PNC, Riverside Furniture, The Rachlin Group, Serta, Shillington Box Company, Universal Furniture, and Weintraub Advertising.

**CHARITABLE CONTRIBUTIONS** arrived in generous proportions from the following donors: Albritton Finan-

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**John Mozeliak and Richard Mackey**

Steinbach, Frank Thurman, Dan and Sue Touchon, Dan White, Mark White, Whitewood Industries, Jim Wilson, Dr. Allison Wright, Rusty Yost, and Marty Zygmund.

**AUCTION ITEMS** were donated by Autohaus (Rusty Yost), Boat House at Forest Park, Culpeppers, Dewey's Pizza,

Five Guys Burgers and Fries, Franco's, Garden Villas South, Golf Discount of St. Louis-Manchester, Art Harper of Garland Wines, Grassi's West, John Mozeliak and the St. Louis Cardinals, Nico's, OB Clark's, Pumpernickle's Deli, Seeger Toyota (Tom Seeger), Bob and Lynda Wiens.

Caps off to these special **VENDORS** who willingly came out of the rough and sank the putt through these in-kind donations: **Alphagraphics (Bob Sanderson)** for the wonderful invitations, flyers, and program booklets; **Fastsigns of Bridgeton (Barry Roufa)** for the wonderful signage, **Paramount Apparel International (Alex Levinson)** for the embroidered navy golf towels; **Blackrock Asset Management (David Rentfrow)** for the sleeves of golf balls for our golfers; and **Golfsmith** for their \$10 gift cards for each golfer.

Our sincere gratitude for the delicious lunch on the course provided by **Crazy Bowls & Wraps**, **Flemings Prime Steakhouse & Wine Bar of Frontenac**, **Donatelli's Bistro of Lake St. Louis**, **Viviano's Festa Italiano of Chesterfield**, **The Ritz Carlton of St. Louis**, and **Garden Villas Retirement Communities**. Our generous hole-in-one sponsors **Autohaus** (much coveted

*continued on next page*



**Brook Dubman**



**John Hogan**



## GOLF TOURNAMENT

*continued from previous page*

323i), and **David Kodner Personal Jeweler** (the 3-carat diamond). Photos were courtesy of **Joanna E. Kleine Photography**, who is responsible for the pictures both on our web site and in this article.

None of this could have been accomplished without the hard-working **volunteers** under the direction of Golf Committee Chairman Brook Dubman: Courtney Taylor Adams, Ann Cook, Elaine Dreher, Debbie Guyer, Christine Karsh, Matt LaMartina, Christine Sadler, Bob Sanderson, Sandy Steppig, Carrie Taylor, Terri Taylor, Donna and Stan Wilensky, and Marilyn Warren. A big thank you for our tireless volunteers from **Scottrade** who spent the day with us at registration preparing and distributing the goody bags for our golfers and on the course: Angie Fossland, Chris Foster, James Kroner, Dodie O'Malley, Jami Payne, Julie Phillip, Jen Summers, Melissa Sweet, Johnny Taylor, Gary Tittel, Nikki Wampler, and Debbie Weaver. Amazing were our auction room volunteers Sandy Steppig, Marilyn Warren, and Lynda Wiens, and Terri and Carrie Taylor, and Courtney Taylor Adams who drove the beverage cart providing beverages and snacks on



**John Mozeliak**

the course throughout the day.

Thank you to the 92 golfers who had an awesome day on the greens, bidding on many wonderful auction gifts, feasting on the prime rib buffet, and enjoying the Question & Answer session with John Mozeliak before he headed off to the ballpark for the game. We marveled at the ease at which Matt LaMartina, auctioneer-extraordinaire, secured bids for our one-of-a-

kind live auction items including an autographed Lance Berkman bat; four field box tickets with four passes for dinner in the Champions Club, and a one-of-a-kind experience-St. Louis Cardinals-baseball-like-never-before evening which included 4 box seats, 4 field passes for batting practice and a group photo on the field, a short stadium tour en route to spending the first three innings of the game in the GM's private box. Dinner and drinks served in the GM's box. Additional auction items included a Bubba Watson ball and photo,

**Bill Billings, Rusty Yost, David Dankmyer, and Chuck Hall**

David Freese autographed jersey and world series ball, Tony LaRusso autographed ball and photo, T.J. Oshie autographed photo, Jaroslac autographed jersey, and an autographed Stan Musial bat.

If you would like to volunteer to join our golf committee or wish to receive an invitation for next year's golf tourna-



**Matt LaMartina, Past President, St. Louis Chapter**

ment, auction, or dinner, be sure to call the center at 314-362-3299 or email [drehere@neuro.wustl.edu](mailto:drehere@neuro.wustl.edu). ■

## USEFUL LINKS

*continued from page 6*

See recently added links under the *Recent News* tab on the homepage of our website, [www.stlapda.org](http://www.stlapda.org):

- Charlie Rose interview on Parkinson's and Huntington's Disease
- Bill Geist interview, Keeping Parkinson's Disease a Secret
- Dave Iverson PBS Frontline program, "My Father. My Brother and Me." ■

# LSVT BIG: FREE INTERACTIVE SYMPOSIUM ON MOVEMENT DISORDERS AND PHYSICAL & OCCUPATIONAL TREATMENT FOR PEOPLE WITH PARKINSON DISEASE

**Crowne Plaza  
St. Louis –Clayton  
Sunday, September 30, 2012**

- 12:30-1:30 p.m.  
*Lecture and refreshments*
- 1:30-2:30 p.m.  
*Interactive demonstration  
with LSVT BIG*

RSVP to LSVT Global  
at 1-888-438-5788  
or email: [info@LSVTGlobal.com](mailto:info@LSVTGlobal.com)

The LSVT Programs for individuals with PD have been developed and researched over the past 20 years beginning with a focus on the speech motor system (LSVT LOUD) and more recently have been extended to address limb motor systems (LSVT BIG).

This presentation will:

1. briefly explain recent advances in neuroscience that have had a positive impact on the field of rehabilitation for individuals with PD.
2. discuss the development and data on an efficacious speech treatment LSVT LOUD.
3. describe development and key aspects of the limb motor treatment LSVT BIG.
4. briefly describe the LSVT HYBRID approach (simultaneous delivery of BIG and LOUD).
5. highlight future directions for innovative technology to enhance accessibility of treatment for all individuals with PD who can benefit. ■

## APDA LOAN CLOSET

*Our loan closet, maintained at Medical West Healthcare Center, on Dielman, contains the following items which have been donated to the St. Louis Chapter. If you are in need of an item not found on this list, don't forget about St. Louis H.E.L.P. (health equipment lending program at 314-567-4700) whose warehouse is open to those in need of medical equipment on Wednesdays and Saturdays. For further information about either of these programs, call the Center at 314-362-3299.*

- Oxy-Cycle Motorized Pedlar
- Foot Bath Massage
- 16x16 E&J wheelchair
- Invacare Folding Rollator
- Commode (3)
- Full Electric Bed (2)
- Semi Electric Bed (2)
- Jazzy 1143 Power wheelchair
- Jazzy 1103 Ultra
- Nova Rollator
- Pronto M71 Power Wheelchair (2)
- Jazzy 600 Power wheelchair
- Bruno Wheelchair Lift

## REGISTRATION

FOR APDA SUPPORT GROUPS, EXERCISE  
CLASSES, AND WELLNESS CLASSES

*With the opening of our St. Louis APDA Community Resource Center in Chesterfield, we will be offering a wide variety of patient services (some familiar and some new), so be sure to check what is of interest to you, so we may get you scheduled into our fall line-up of classes being held at the Resource Center in Chesterfield.*

*Circle the programs you are interested in and you will be contacted with information and meeting dates/times/places for the fall sessions.*

I am interested in learning more about the following programs:

- PD101
- Tai Chi
- Adult Children of Parents with PD
- For Caregivers Only
- Dance
- Exercise Classes
- Loud Crowd/Voice Aerobics
- Wellness Course
- Chesterfield Exercise Class
- Yoga
- Support Groups
- Aquatics

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

*Please return this form to the **APDA Information & Referral Center, Campus Box 8111, 660 S. Euclid Ave., St. Louis, MO 63110** OR fax to **314-747-1601** OR email to [guyerd@neuro.wustl.edu](mailto:guyerd@neuro.wustl.edu). Please call with any questions: **314-362-3299**.*

Washington University School of Medicine  
American Parkinson Disease Association  
Campus Box 8111  
660 S. Euclid Ave.  
St. Louis MO 63110  
Address Service Requested

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## GOT MAIL?

Publishing and mailing these newsletters exceeds \$1.00 per magazine.

If you no longer wish to receive this publication or other mail from the Greater St. Louis APDA, please email [drehere@neuro.wustl.edu](mailto:drehere@neuro.wustl.edu) or call (314) 362-3299 and your name will be removed immediately.

To reduce our costs for newsletters returned with incorrect addresses, please inform us of any change in your address so that we can ensure you receive the newsletter.

We're excited to bring you a delightful afternoon of fashion, delicious food, and a silent auction filled with goodies and one-of-a-kind items. Proceeds from this event will be used exclusively for funding research conducted at the local Center for Advanced Parkinson Research to identify causes and ultimately a cure for Parkinson's disease.

Invite your family, friends, and neighbors!

We're thrilled to have Victoria Babu, KTRS 550 a.m. News Director, serve as our Master of Ceremonies, and to present the fall fashions from some of St. Louis' premier boutiques. Honorary Chairpersons are Steve Hurster, President and CEO of Bohn and Dawson, and his wife, Lynn.

Doors open for the silent auction at 10:30 a.m., the luncheon will begin at 11:45 a.m., and the fashion show starts at 1:00 p.m on October 8, 2012 at the

## OCTOBER 8, 2012: THE 17<sup>TH</sup> ANNUAL APDA FASHION SHOW



# SWEET SUCCESS

Sheraton Westport. The cost remains \$60 per person.

Would you like to help make a big impact on this important fundraiser? Please consider becoming a *sponsor*. As a sponsor, you or your business will receive promi-

nent placement in our program and on signage, plus special seating at the fashion show. Sponsorships begin at \$500.

For more information about the fashion show and sponsorships, visit [www.stlapda.org](http://www.stlapda.org) or call the APDA office at 314-362-3299. If you haven't received an invitation for past fashion shows and would like to receive one this year, please send us an email at [karshc@neuro.wustl.edu](mailto:karshc@neuro.wustl.edu) or give us a call. We'll gladly include you on our guest list. We hope you and your friends will join us to make this year's fashion show a sweet success! ■