

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

Serving Missouri and Southern Illinois

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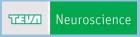
APDA Greater St. Louis Chapter

1415 Elbridge Payne Road, Suite 150 Chesterfield, Missouri 63017

314.362.3299 | www.stlapda.org

OUR MISSION

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



The printing and distribution of this newsletter was partially supported by a grant from TEVA Pharmaceuticals.

Another Favor to Ask

Debbie Guyer, MA, Executive Director, Greater St. Louis APDA



Debbie Guyer

We had such a favorable response to the front page article in the May newsletter requesting that you take a Parkinson Journey DVD to your own physicians, I am returning to ask for yet another favor.

I'd like you to not only advocate for yourselves, but advocate for others with Parkinson disease (PD). Tell your physicians (primary care physician, neurologist, psychiatrist, or movement disorder specialist) how you have benefited from your association with the APDA Greater St. Louis Chapter. Perhaps it has been through reading our quarterly newslet-

ters, receiving an information packet filled with literature and pamphlets on shared cost services, taking the introductory session (PD101) for newly diagnosed patients, participating in one of our 34 support groups, attending our weekly exercise classes (chair exercises, Tai Chi, or aquatic exercises), or the recent wellness class. Pay it forward by reminding your physicians of the value of getting you or someone you love connected to APDA. We feel this will have an even greater impact that will hopefully result in a referral to our organization the next time they see the next patient with PD (newly diagnosed or someone who has had PD for a number of years). Tell your children, too, because they are interested in learning more about PD and how you are reclaiming your future and working to live *well* with this disease.

On another note, we need your connections! Corporate and community partners help underwrite APDA patient services, fund research, and support the work done at the Parkinson Community Resource Center on behalf of patients and their families throughout Missouri and Southern Illinois. If you, your child, or a friend is connected to a corporation, small business, or foundation, please let us know so that we can approach them for a sponsorship or contribution for one of our fundraisers. We are never afraid to ask on behalf of APDA. Our fundraising efforts were extraordinarily successful this year because of the generosity of so many new corporate and individual sponsors (see golf article), and new participants at these events. Thanks to your participation, over \$117,000 was raised at our fall fashion show and luncheon last October and over \$110,000 at our golf tournament this past May. We can accomplish so much more by reaching out to others in our philanthropic community and networking. There is exciting research to be funded and new patient programs being developed to meet the needs of those we serve. Your support of our local efforts through sponsorships, attendance at fundraisers, participation in an Optimism campaign, or monthly contributions translate into more services being offered to our constituents. PD is a life changing battle requiring resources beyond expectations and we are fortunate to have generous supporters like you and are seeking even more partners.

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Disclaimer: The information and reference material contained herein concerning research being done in the field of Parkinson disease and answers to readers' questions are solely for the information of the reader. It should not be used for treatment purposes, rather for discussion with the patient's own physician.

Board Briefs

Tom Mackowiak, 1st Vice President of the APDA Board, made the decision to step down from the Board as his term ends in August after 13 years of continuous service to the Greater St. Louis Chapter of the APDA.

"Our organization has truly evolved over the past several years and we are taking the support to another level. I have been blessed to be associated with a group of dedicated individuals who are truly working to ease the burden and find a cure. It takes a whole team of people to make an impact, and that list not only includes our director, staff and board, but our advisors, our volunteers, all those who have supported APDA with their time and/or talent, and those who have donated money and continue to donate. I hope you are as proud of what we have accomplished as I am, and as excited about the future untapped opportunities ahead. The changes at the national level appear to be promising and beneficial for the local chapters."

Tom got involved with APDA after his mother was diagnosed with Parkinson disease, and she continues to fight a good fight as best she can. Tom has pledged to continue to support the Chapter's efforts to educate and build awareness, as well as funding research and patient services. We

thank Tom for all he has done and continues to do to make a difference in our community. We learned a great deal from his involvement on the Board, and his diplomacy and thoughtful insights will be missed. We wish him only the best in his future endeavors.

Lynda Wiens has also stepped down from her position on the Board having served for almost 10 years. Lynda will continue to focus her energies on volunteering at the Resource Center, continuing to co-facilitate the Caregiver Only Support Group, and creating lovely and entertaining auction baskets for our Fashion Show and Golf Tournament. You will recall that Lynda's \$10,000 grant (an award she received as Volunteer of the Year in 2007) was immediately provided to our Greater St. Louis Chapter which enabled the Chapter to establish a Chesterfield Resource Center, fully furnished with the desks, computers, storage cabinets, bookshelves, conference table, and chairs that are still being used today in our Center. We will be welcoming four new board members in September. They are Anne Ross-Weldy, Dave Butler, Ted Hume and Matt Schumacher. Our next newsletters will have more information on Board members who volunteer so much of their time and talents to the Greater St. Louis Chapter.

Tell Us Something Good

Don Donlon, St. Charles Support Group

We often wonder what to say, when folks ask how we feel.
Our answer's usually nonchalant; it's really no big deal.
We say we're fine, that's good enough, that's all they have to know.
No sense in spouting out the words we harbor deep below.

When we were young and full of grit, nothing did we fear.
Now every day is precious, and every moment dear.
We now possess a grand respect for family and friends.

It's from these folks our life does reap unending dividends.

There's tons of print, a million words, nothing surely new.
We take our meds and see the doc, that's what we're told to do.
Some days are good, some days are not, we never know for sure.
We simply hope to see the day, they tell us there's a cure.

So we'll proceed full speed ahead, and take things as we should, While sitting and a-waiting 'til they tell us something good.

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Questions for the Doctor



Pratap Chand, MD, FRCP, Professor of Neurology, Director, Movement Disorders, Department of Neurology & Psychiatry Leah Cuff, APRN, ANP-BC, Nurse Practitioner, Department of Neurosurgery, Department of Neurology & Psychiatry, Saint Louis University (cuffle@slu.edu)

Dr. Chand

My husband takes Midodrine and pyridostigmine for low blood pressure, but he still faints two or three times a day. Is there anything else to help him with his dropping blood pressure?

A fall in blood pressure on standing (orthostatic hypotension) is a non-motor symptom of Parkinson disease and more so in a Parkinsonian syndrome called Multiple System Atrophy (MSA). It can be from the heart rate not increasing when standing up as it does in a non-Parkinson person. It can also be from the medications that treat the symptoms of Parkinson disease, e.g. ropinirole, carbidopa/levodopa, and pramipexole. There can also be additional causes such as dehydration, fever, low hemoglobin (anemia), or the use of certain medicines like diuretics (water pills), betablockers or vasodilators used to reduce blood pressure. Check to see if you are on any of these medicines and if so, discuss with your primary physician if their use can be modified.

In addition to the medications Midodrine and Pyridostigmine that you are using to increase his

is Chapter

blood pressure, you can also ensure that he stays well hydrated, avoids heat exhaustion, does not consume alcohol, prevents standing too long, minimizes straining in the bathroom, and reduces high consumption of carbohydrates at mealtimes. The use of stockings on the legs and getting up slowly from a lying-down position especially in the mornings when he awakens can help to

prevent the sudden fall in blood pressure. If these measures do not help, another medicine that can help is Fludrocortisone. Again, it is advisable that you discuss with your providing physicians if he will benefit from this medication. When using these medicines to increase blood

pressure, it is important to check his blood pressure when lying down to make sure that it does not go too high (supine hypertension).

Will it hurt to take a day off from medication (Sinemet)?

It is not recommended that you suddenly stop Sinemet. It can lead to a serious condition called Parkinsonism Hyperpyrexia syndrome. The symptoms of this include fever, muscle stiffness, confusion, difficulty with heart rate or blood pressure, and sweating. If you wish to reduce or change the dose of any of your Parkinson medications, you should contact your neurologist who can advise you how to slowly come down off the medication, if indicated.

Please discuss what the common vision problems are in people with PD and what treatments are recommended for these visual disturbances. I understand some patients have prisms-why?

There can be many reasons for vision problems in Parkinson disease. They could result from a lack of dopamine in the retina or a decrease in the movements of the eye or a decrease in blinking. These can result in changes in vision including processing what is being seen, light/dark sensitivity, altered color vision and impaired ability to recognize facial expression of other people. Prisms may be necessary to assist in correcting the vision when the patient is seeing double. Visual hallucinations and illusions may be related to PD medications. Treatment would depend on the cause of the visual disturbance. Please discuss this with your provider. An examination by an ophthalmologist is a good starting point to make sure that the visual problem is not due to common eye disorders.

Why do I have periods of intense sweating several times a day, lasting for 15-30 minutes at a time?

Hyperhidrosis (excessive sweating) can be a non-motor symptom related to autonomic dysfunction in Parkinson disease. It can be an "off" symptom when the PD medicines like Levodopa wears off. It can also be from excessive dyskinesias or tremor. The first step is to keep a diary and identify if the excessive sweating in your case is due to wearing off or due to dyskinesias and then to have your medications adjusted accordingly by your provider. Adequate hydration, wearing light summer clothes, and keeping the room temperature cool in your home and office environments can help.

Dancing with Outliers



Pamela Quinn

Pamela Quinn has been developing approaches to movement for people with Parkinson disease for the Brooklyn Parkinson Group and for the NYU Parkinson Wellness Program for many years through her class PD Movement Lab. She speaks and teaches around the country (she was here in St. Louis last year) and is also known for her award winning video, "Welcome to our World."

Dance, I have learned,

retrieving many of the

functions Parkinson

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is an ideal tool for

When we study history's political figures, we analyze our heroes: Lincoln, Susan B. Anthony, or Martin Luther King. When we listen to famous composers, we gravitate toward the genius of Mozart, Beethoven, or Schubert. And in science, we appreciate the mental wonders of Einstein and Newton. We look to these exceptional individuals for what they can teach us about how to function at optimal levels in very different human activities.

In the study of individuals with a disease, we can follow this same practice. We stand to learn a great deal from the success certain patients have in dealing with an illness that cripples others. This is especially true for those with chronic conditions. If we can discover common denominators among these patient "outliers," we may be able to help others achieve similar results. Can we devote as much attention to the components of optimum health in those who must live with disease as we do to the damage disease causes?

I consider myself one of these outliers in the realm of Parkinson disease. I was diagnosed 16 years ago at the age of 42, and I am still quite functional, meaning that I am able to work, be physically active, and participate fully in family life. Like all other PD patients, I suffer a variety of symptoms. I have tremors and muscular rigidity. I struggle with slowness and interruptions of movement and balance. But I have been able to control my symp-

toms and to inhibit their progress to a greater extent than many of my fellow patients. And I've had to ask myself why.

One reason is already well known: early onset Parkinson disease generally progresses more slowly. Had I developed the disease when I was in my 60s or 70s instead of my early 40s, my symptoms would likely have progressed much further in a decade and a half. Those with early onset also tend to respond better to medication, both in the short term in the degree of symptom control and in the long term in how many years a drug will remain effective. Relative youth also generally has the advantage of better overall health. The effects of aging only compound the problems of Parkinson disease.

But there are other factors that I believe have contributed to my comparative good fortune. They have to do with the plasticity of the brain and how we can circumvent the physical and mental obstacles Parkinson disease presents us with. PD disrupts our normal neural circuitry, but we can develop alternative measures — cuing systems — to initiate and control movement, and we can substitute conscious activity for what was once the responsibility of the autonomic nervous system. Instead of relying on the usual nerve signals that come from the brain, the body works with other modes of communication to approximate the same results. Musical cuing, visual cuing, the use of touch, and other sensory feedback are all other means of retraining our brains in how to talk to our muscles.

When I was diagnosed with PD, I already had the infrastructure of those systems in place, and I knew how to use them. Why? Because I was a professional dancer.

Dance, I have learned, is an ideal tool for retrieving many of the functions Parkinson disease takes away. In combination with music, it uses auditory cuing to both initiate and organize movement and to propel you through space. It uses visual cuing in learning movements by watching others and in initiating movement in relationship to others. It also frequently uses touch: when you partner with another person, you receive signals as to how and when to move. In addition to its use of these cuing systems, dance also creates understanding of the mechan-

ics of posture and balance. You are constantly working with a mirror and learning to feel how the body is placed. Dance also requires memorization of sequences (executive function), with retention of information aided by extensive repetition. Perhaps most important of all, the discipline of dance involves the practice of conscious movement every day – you are always asking your body to move in a particular fashion and through a specified sequence of moves. You are constantly directing it, talking to it.

fied sequence of moves. You are constantly directing it, talking to it.

Parkinson disease diminished my natural capacities for movement in large and small ways. But because of my background in dance, I had a host of skills and a nervous system supplied with useful detours already in place and operating. It is no wonder that I had an advantage over others.

It took me some time to recognize and articulate the factors in my situation that proved so helpful in dealing with my PD.

I was practicing them before I really began to understand their full significance. But I now have many years of seeing them in action and seeing their results. My hope is that research will begin to focus much, much more on the potential of dance and

continued on next page

other methodologies to change the way Parkinson disease is treated.

I've had people come up to me and say, "What do you do? I want to be like you." What they want is to understand the tools used to manage the disease over an extended period of time. What are the factors that can make one person relatively able while another may struggle with the most basic aspects of functioning?

Medication, of course, plays the most essential role in managing symptoms. But medications are still inadequate. They work incompletely and for limited amounts of time. And the vast majority of patients still suffer degrees of disability which rule and constrict their lives. There is a desperate need for additional tools to deal with symptoms and a desperate need to understand how PD can result in such variable conditions. Understanding how the most successful patients, the PD mavericks, fare offers a potential entre into this mystery.

A well known neurologist who heads a major PD center in New York once said to me that there were patients who do poorly with Parkinson disease and those who do surprisingly well, and we just cannot explain why. Let's marshal our resources to find the answer – or answers - to that question. And a good place to begin is to examine in exhaustive detail the conditions and practices of the outliers among us. To that end, I extend an invitation to all who are willing: come dance with me. ■

This article first appeared in the spring 2013 issue of Neurology Now.

Optimism Reigns!

What an extraordinary quarter of Optimism Events and donors to recognize in our special Optimism campaign section!

Mark and Mary Whitehead had a marathon of events in April to highlight Parkinson Awareness month. The Whitehead's 'Shaken Not Stirred' campaign included raising not only money, but also awareness of Parkinson disease. The list of events included a Lunch & Learn program at Mary's employer, Ameren headquarters; the Mayor's Proclamation in Granite City of April Awareness of Parkinson disease; planting tulips for PD in the Park District; a Pancakes for PD breakfast at Ameren; a display at the Granite City library; and a sale of t-shirts and tote bags designed by Jon Rogles and produced by a print shop owned by Mark and Mary's classmates. In addition, April activities included dinners at all three Ravanelli Restaurants on the east side (O'Fallon, Collinsville, and Granite City, IL), where 10% of the proceeds from dining in were donated to the APDA Greater St. Louis Chapter, serving Missouri and Southern Illinois. Mary also quilted and embroidered a raffle gift in addition to securing gift baskets also raffled at Ravanelli's. This April awareness blitz, along with contributions from many personal friends, resulted in over \$3,000 being donated for local Parkinson research in Mark's honor and out of their own appreciation for Mark's physician, Dr. Joel Perlmutter, the very caring Nurse Practitioner, Johanna Hartlein, and the entire team at Washington University School of Medicine, Advanced Center for Parkinson Research.

A charity jeans day and adult Easter egg hunt resulted in **Cindy Ebert** donating \$282 in loving memory of her father, Edwin Fox, who suffered from Parkinson disease for 10 years. Money was collected from employees of Evans & Dixon LLC.

Tom Lane and Michael Jersa are to be congratulated for their efforts in personally selling 87 tickets for the sold out Queen of All Saints Variety Guild performance, which resulted in a \$1,740 contribution to the APDA Greater St. Louis Chapter. They have promised to do it again next year with your help.

For more information about hosting your own **Optimism event**, contact the APDA office at 314-362-3299.



The Optimism Campaign recognizes individuals or companies who contribute \$500 or more during each calendar year. These members represent January 1, 2013 to June 30, 2013.

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Depression in Parkinson Disease



Dr. Black

Kevin J. Black, MD, Professor of Psychiatry, Neurology, Radiology and Neurobiology, Washington University School of Medicine, St. Louis, MO

any patients with Parkinson disease develop depressive symptoms severe enough to discuss with their physician. Below I will address

some of the questions we hear from patients and families about depression in Parkinson disease.

Is this a big problem?

Roughly 40% of PD patients develop a degree of depression that requires medical attention. We all know that when you feel bad everything seems worse. People with depression are more likely to notice their bodily symptoms and more likely to feel that they can't do what they would like to because of them. More importantly, major depression is a miserable illness. For many patients, the depressive symptoms are a bigger problem than the trouble moving.

What can you do about depression in PD?

This depends on the pattern of the depressive symptoms. Some of these patterns (syndromes) are described below. A physician experienced in PD can help you sort these out.

Medication-related mood fluctuations: If you predictably feel down, sad or anxious when your Parkinson medicine wears off, but fine (or even a little "high") the rest of the day, this is a known complication of PD. It affects perhaps 5-10% of people with PD, though many people have not heard of it. For these dose-related mood fluctuations, the ideal treatment is to attempt to smooth out your anti-PD medications' effect throughout the day. This is done on an individual basis with your doctor, but some of the available strategies include larger doses, addition of a medicine like selegiline or tolcapone that slows the metabolism of levodopa, or use of a long-lasting medication like slow-release carbidopa-levodopa or a dopamine agonist.

Easy crying: Fairly commonly, people with early PD notice that they cry more easily "out of the blue" at movies or at other times, even if they're not really sad. Less often people also find themselves laughing when nothing is very funny. This pattern of easy crying is probably due to loss of dopamine input to the part of the striatum that controls the brainstem, where our laughing and crying reflexes are located. It usually responds to PD medications or to a rather low dose of an antidepressant.

Apathy: Many people with PD lose interest in things and feel unmotivated. Often this comes with other symptoms of major depression, and then the depression should be treated first. Other times the apathy comes on its own, without other fea-

tures of major depression. Often the family says, "he looks depressed," but the patient says no and is content to just sit there most of the day not doing anything much. In this case, apathy is a symptom of PD. Sometimes it responds to increasing the PD medications.

Steady sadness: If you are sad or disinterested in things most of the day, nearly every day, for weeks on end, you may have major depression. This is a real medical illness and should be treated. About one in four PD patients has major depression. In my opinion, you deserve specialty care from a psychiatrist if you are depressed and any of the following apply: you are not better after 4-6 weeks of any treatment, you are disabled by your depression, you are thinking about suicide, someone in your family has manic-depressive illness, you have hallucinations, or you wish to be treated with counseling rather than with medications. There are many treatment options for depression in people with PD. Usually we add an antidepressant medication. Recently several studies have shown that depression in PD benefits from various antidepressants.

The most commonly used antidepressants in PD include SSRIs (e.g. selegiline, escitalopram), SNRIs (e.g. venlafaxine, duloxetine), and mirtazapine. Most PD patients tolerate these medications well. If you are taking an MAO inhibitor (selegiline or rasagaline), you should discuss a side effect called serotonin syndrome with your doctor before starting an SSRI or SNRI. However, many patients take both without noticing any problems. It often takes 4-6 weeks of an adequate dose to see complete results. Many patients also benefit from expert counseling, say every week or two for 2-3 months. Most people are helped by one of the foregoing options, but if not, we have other tricks up our sleeves. Recently a specific kind of short-term counseling (cognitive-behavioral therapy) was proven to be helpful for major depression in PD. Some patients benefit from a hospital stay. The most effective treatment for major depression is ECT (electroconvulsive therapy). Although ECT has had a lot of bad press, most criticisms are seriously out of date. Modern ECT is one of the safest medical procedures and even reduces parkinsonism temporarily. The bottom line is that most PD patients with major depression can be treated successfully, one way or another.

Normal sadness: If you get down sometimes, feel frustrated with your symptoms and how they affect your life, and have trouble falling asleep from time to time because you are thinking about the real problems in your life, but you are fine most of the day, most days, and you don't have one of the syndromes described above, this is not necessarily an illness. No one has a corner on how to treat it, but answers include talking to friends, family, or religious leaders about how you feel; doing things you usually like; and picking up new hobbies, work or volunteer activities (an occupational therapist can be very helpful in this regard). Professional counseling may also be helpful.

continued on next page

What causes depression in PD?

Experts talk about three possibilities.

- **1.** It is just a coincidence since both Parkinson disease and depression are common.
- 2. We already know something goes wrong with the brain in PD, and since the brain is what makes us happy or sad, depression is just another symptom of PD.
- **3.** Of course, people get sad. Who would want to have a physical illness?

In an individual person, we cannot usually sort out these three possibilities. However, research can help us figure it out in general. Here are my conclusions from my experience and from published research.

- 1. Some people are going to be depressed with or without PD. They may have already had major depression earlier in their life, or it may run in their family.
- 2. In many people, depression is clearly a symptom of PD. Reasons for saying this include that major depression is more common in PD than in people with non-brain diseases like arthritis. It happens equally in men and women with PD whereas generally depression is twice as common in women. Its symptoms are different from those of ordinary major depression in certain ways. It can start for the first time late in life when things are going well, and the person has weathered many life storms without depression, and it can start before the person even knows he has PD.
- 3. Almost everyone with PD has mild sadness and frustration from time to time, and that may be normal. But when the depression is there most of the time or is interfering with your life, you deserve expert help. ■

This is an update of an article originally published in our newsletter in 1998.



Mark your calendar for our 18th Annual APDA Fashion show/luncheon/auction on October 14, 2013!

Focus on Fashion & Philanthropy

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 to support APDA's mission—"to ease the burden and find the cure" through expanding patient services and Parkinson research, which seeks to identify causes and ultimately a cure for Parkinson disease. Invite your family, friends, and neighbors!

We are thrilled to have Victoria Babu from KTRS and Courtney Landrum from Y98 serve as our Masters of Ceremonies and to present fall fashions from some of St. Louis' premier boutiques and designers.

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 14, 2013, at the Sheraton Westport Chalet. The cost is \$65 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 prominent 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 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 brooksmi@neuro.wustl.edu or give us a call. We'll gladly include you on our guest list. We hope you and





APDA-Greater St. Louis Chapter August 2013 LINK

Honoring the Memory of Our St. Louis Treasure, Jack Buck, at the 2013 APDA Memorial Golf Classic



John Mozeliack, Honorary Chair

his year's Jack Buck Memorial Golf Classic was a record fundraising success, as we raised \$110,000 for Parkinson research and patient services. The event, with the assistance of John Mozeliak, Dan McLaughlin, and the Jack Buck family, also increased the awareness of PD. We managed to dodge the rain and had a beautiful spring day at Algonquin Golf Club in Glendale.

Our success was due in large part to our loyal sponsors, both new and those who support us year after year: CELEBRITY level sponsors: Community Partnership at Benton Homebuilders and Wells Fargo Commercial Banking; MAJOR level sponsors: Brinkmann Constructors, Mark Burkhart, Carol House Furniture, Moneta Group, LLC and Sterling Bank; GOLF CART sponsors: Barnes-Jewish Hospital and Schumacher Creative PR; CONTEST

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CHARITABLE CONTRIBUTIONS arrived in generous proportions from the

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PRACTICE

Caps off to these special VENDORS who helped make the event a success: St. Louis Rams Cheerleaders for their appearance; Crown Trophy for the golf awards and crystal

plaques; Dave Peacock and Joe Pfeiffer for beverages on the course; The Delmar Gardens Family for the cooler of fun raffle; Edwin Watts Golf and Golfsmith for gifts for golfers; Autohaus BMW for the hole-in-one car and sleeves of golf balls for our golfers; David Kodner Personal Jeweler for the hole-in-one three-carat diamond; Dan McLaughlin and John Mozeliak for media/marketing leading up to the event; Joel Marion Photography and Sara Tegman Photography for their services that day; Alphagraphics, Aimee Bachman, and Kopytek for printing and

design; Simons Jewelers for the Rolex raffle; Fastsigns of Bridgeton (Barry Roufa) for the wonderful signage; and Pretzel Boy's (Tim Garvey) for snacks on the course.

None of this could have been accomplished without the hard-working

Drs. Ushe. Norris. Perlmutter & Nathan Perlmutter



volunteers under the direction of Golf Committee Chairman Matt LaMartina: John Basilico, Kay Bruchhauser, Rebecca B. Farris, Bob Goldsticker, Karl Guyer, Michelle McDonald (National APDA VP), Craig Miller, Dwight Rasmussen, Sherrie Rieves, Barry Roufa, Dave Sodemann,

Carrie Taylor, Terri Taylor, Marilyn Warren, and Lynda Wiens. A big thank you to our tireless volunteers from Scottrade who spent the day with us as part of their day of service: Matt Black, Patty Boehm, Andrea Cross, Mary Ferry, Sandra Janik,



Ross Schumaker & Mark Kodner

Tom Kriss, Jason Mayer, Catherine Maher, John Rapisardo, Brett Rippelmeyer, John Stieven, Mary Lou Sullivan, Jen Summers, and Kyle Townsend. And finally, thanks to the staff of APDA: Michelle Brooks, Elaine Dreher, and Debbie Guyer who made sure everything ran smoothly.



Dan McLaughlin

Thank you to the 140 golfers who had a great day on the greens at Algonquin, bidding on many wonderful auction items, and enjoying the Question and Answer session with John Mozeliak and Dan McLaughlin. Auctioneer-extraordinaire (and broadcaster) Dan McLaughlin secured bids for our one-of-a-kind live auction items including a signed and framed copy of the Jack Buck 9/11

poem; signed jerseys of Stan Musial, Yadier Molina, and Adam Wainwright; and an experience donated by Dan: the opportunity to throw out the first pitch at a Cardinals game along with access to the broadcast booth. Additional auction items included a Tarasenko Blues jersey, 2011 World Series scorecard signed by David Freese, many sets of Cardinal baseball tickets and suites, and signed baseballs from Adam Wainwright, Shelby Miller, and Jason Motte. Silent auction gifts included a gift card to Golf Discount of St. Louis; rounds of golf at area courses (Algonquin, Greenbriar Hills, Innsbrook, Lake Forest, Old Warson, Persimmon Woods, and Sunset Hills); baseball bats signed by Carlos Beltran, Matt Carpenter, David Freese, Matt Holliday, and Yadier Molina; and Victorinox luggage. The evening was capped off by an emotional and meaningful testimonial from Christine Klein who was diagnosed with Parkinson disease in her 30s. She shared her hopes of someday finding a cure, being able to see her children graduate, and dancing at their weddings.

If you would like to volunteer to join our golf committee or wish to receive an invitation for next year's golf tournament to be held on Monday, May 19, 2014 at Algonquin Golf Club, be sure to call the center at 314-362-3299 or e-mail brooksmi@neuro.wustl.edu.

New Clinical Trial Opportunities

Parkinson Disease and Wearing Off

Dr. Brad Racette at Washington University School of Medicine is participating in a research study investigating a drug called CVT-301 for those who have Parkinson disease and are experiencing wearing off periods between their levodopa doses. The pill form of levodopa is currently approved by the FDA for the treatment of PD symptoms. The study drug, CVT 301, is considered investigational and is levodopa in powder form. It is inhaled through an inhaler. Many PD patients take levodopa as a pill at least four times a day, but still experience periods of "wearing off" (called OFF episodes) between their usual doses. The primary purpose of this study is to see if the study drug CVT 301, when inhaled through an inhaler, will provide faster relief of motor fluctuations (OFF episodes) when compared to a placebo (no active drug) in patients with PD.

To take part in the study, individuals must be between 30 and 80 years old with a diagnosis of PD and are experiencing wearing OFF of their PD medications. Participation will last approximately 8-10 weeks and includes up to seven office visits. For more information, please contact Karen at 314-747-0514 or mcdonellk@neuro.wustl.edu.

Exercise Study

Dr. Gammon Earhart, Associate Professor of Physical Therapy at Washington University School of Medicine, is conducting an exercise study for people with Parkinson disease. Dr. Earhart and her colleagues are interested in seeing how exercise can be used to change things like walking, balance, and brain activity. This study has participants coming in for one hour twice a week for three months to dance the tango or walk on a treadmill. The classes are held near the Barnes-Jewish Hospital campus, and parking is provided. Participants will come in for a physical evaluation and an MRI before and after three months of exercising. We also ask them to come back three months after completing the study for a physical evaluation to see if any of the effects have lasted. If you are interested and would like to participate in this study or if you have any questions, please call Martha at 314-286-1478 or email at hesslerm@wusm.wustl.edu.

Fall Detection Device

Washington University School of Medicine, Program in Occupational Therapy, is recruiting for a study to establish the effectiveness of a small fall detection device. Older adults with Parkinson disease who fall frequently may qualify for the study. Participation involves wearing a device 24 hours a day for two weeks (except when swimming or bathing). All study visits will happen in the homes of older adults, and those who participate will be provided with a \$100 participant payment. For more information, contact Jane at (314) 932-1011.

Tributes & Donations 4/11/13 – 7/19/13

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 at 314-362-3299. Contributions can be made directly on the APDA Greater St. Louis Chapter website, www.stlapda.org.

Honoring

The special birthday of Ron Abeles

Nancy & Mark C. Kodner Research Fund

The special birthday of Sid Axelbaum

Steve & Marilyn Dardick Arnold & Marilyn Goldman Fred & Joy Levin

Moury Bass Kay Bruchhauser

PEP presentation by Dr. Kevin Black Debbie Guyer

The swift recovery of David Boxer Penny Kodner

The 60th anniversary of Mr. & Mrs. Brockmiller
Mr. & Mrs. Carl Walker

Velma Buermann
Eugene & Carole Dooley

The 90th birthday of Margie
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The wedding of Nat & Beth Erdman Bonnie Paulsmeyer Bruce & Patricia Williams

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Bill & Terri Taylor

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Mike & Cindy McConnell

Mary Ellen Foland Clifford & Anita West

The special birthday of Roz Gad
Bill & Terri Taylor

Arnold Goldman
Daniel Goldman

The 50th birthday of Jon Goldman Gail, Larry, & Alyssa Glenn

Debbie Guyer Kay Bruchhauser Happy Mother's Day Nancy D. Klein Andrew Klein

Nancy Klein Michael Klein

Mark Kodner
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The Bat Mitzvah of Sharna Kohner Mr. & Mrs. Larry Rogul

Dawn Lintzenich, RNKay Bruchhauser

The special birthday of Eleanor Markow Roselynn Gad

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Phyllis Ross
Doris Ebersole

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The Bat Mitzvah of Samantha Zeid Larry & Gail Glenn

The special birthday of Pat Schark Maxine Gilner

The special birthday of Harry (Buzzie) Schukar Arnold & Marilyn Goldman

Jenny Schweppe Bob Schweppe

Marty Shrader
Judith & Steve Ellenburg
Judy Ugalde

The 60th anniversary of Mr. & Mrs. Sid Silverman Cheri & Steve Lasky

Dr. Todd SilvermanSteve Hurster

Kristie Skor Larry & Gail Glenn

Doug Smith
Bill & Terri Taylor

The anniversary of Terri & Bill Taylor Roselynn Gad

Phyllis Taylor & Ron Elkana's Marriage Roselynn Gad

Elaine Varnadore
Richard & Sharon Holt
Harry & Beverly Lee

Happy Mother's Day Carola Von Berg Janice Raymond John & Ramona Von Berg Angie Wernle, RN Kay Bruchhauser

The birth of Eve Viloria Wiens Debbie & Karl Guyer Robert & Lynda Wiens

Tammy Williams, RN Kay Bruchhauser

The special birthday of Sigrid Woltzen Nancy & Mark C. Kodner

The special birthday of Norma Ziegenhorn

Don Ziegenhorn

Research Fund

Remembering

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Alan & Elaine Bennett
Brookhaven Garden Club
Bob & Lois Estes

Brookhaven Garden Club
Bob & Lois Estes
Peggy Estes
Kathy Fitzgibbons
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continued on next page

Rosi & Gorgi Naumouski

Happy 1st Anniversary Parkinson Community Resource Center!

Debbie Guyer, MA, Executive Director

as I write this article, the country is celebrating its birthday (July 4th), but as you read this newsletter, our Parkinson community will be celebrating an occasion as well: the first anniversary of the opening of our Parkinson Community Resource Center. I had the pleasure of

spending time with a group of doctoral candidate occupational therapy graduate students from Dr. Erin Fos-

ter's lab this past week, and it was with such pride that I gave them the tour and explained all the various activities taking place at our Center. If you haven't stopped by the Center, I encourage you to do so. Bring a friend or your support group

and plan a field trip to Chesterfield where you can visit with staff and meet our wonderful volunteers who reside in this welcoming space.

As I explained to the students, we hold our Caregiver Only Support Group on the second Monday of the month, the Chesterfield Support Group on the first Tuesday of each month, chair exercise classes every Monday afternoon, and Tai Chi classes every Wednesday morning. You will find our fashion show committee planning the October event or making an auction basket. Our staff members are usually able to respond personally to your questions.

I hope we can count on your involvement as we go forward into a new fiscal year. We welcome your participation and look forward to meeting you in person at our Parkinson Community Resource Center in Chesterfield.

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Missouri Support Group Calendar

Sponsored by the American Parkinson Disease Association Greater St. Louis Chapter

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**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	2:00 PM	Gayle Truesdell	636-923-2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street, Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard	314-362-3299
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton Doris Heuer	573-434-4569 573-999-2106
Creve Coeur	St. Louis	Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl. CLI Rm. 419	3rd Tuesday	6:30 PM	Steve Balven Joe Vernon	314-249-8812 636-230-8279
Creve Coeur	St. Louis	Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl.,CLI Rm. 419	3rd Tuesday	6:30 PM	Doug Schroeder Rich Hofmann	314-306-4516 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 x129
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
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816-861-4700 x56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW	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
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	Mercy Hospital 1235 E. Cherokee	Last Thursday	11:00 AM	Kay Meyer	417-350-1665

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August 2013 LiNK APDA-Greater St. Louis Chapter



City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573-543-2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660-357-2283 660-485-6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314-713-4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Wentzville	St. Charles	Twin Oaks at Heritage Pointe 228 Savannah Terrace	1st Thursday	1:00 PM	Ann Ritter, RN Sherrie Rieves	636-336-3168 636-542-5400



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**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
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
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Road	Every Monday	10:00 AM	Charles Rohn Chuck Arbuckle	217-549-6167 217-586-3100
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	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
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. 930 Barberry Dr. , SW Bldg. www.parkinsonssupportcentralill.org	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

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LET'S SING!

Did you know that your favorite music can shape the way you speak, the way you move, and the clarity of your thinking? The APDA of Greater St. Louis would like to offer weekly classes of Music Therapy to patients with Parkinson disease. Participants will learn how to incorporate the joy of music in their daily activities. You will sing, move rhythmically, and play a percussion instrument together with the instructor in a fun environment.

This class will be professionally conducted by a certified Music Therapist, under the medical advice of Anna Conti, MD, PhD. Dr. Conti is a Movement Disorder specialist with expertise in the neurology of music. Dr. Conti works at Mercy Hospital St. Louis, where she also leads a clinic for musicians with neurological problems in playing their instrument.

For more information, please call the APDA 314-362-3299 and register for this exciting opportunity!



Exercise Classes

Our Exercise Classes meet once a week or otherwise as noted. Information that has changed since the last LiNK appears in **bold**. Attend one class per week at no charge or for \$20/month, attend as many classes as you want. No RSVPs are required.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
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	1:00 PM	Brandon Sunderlik Faye Bienstock	618-971-5477 314-917-9983
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday	10:00 AM	Craig Miller	314-362-3299
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Monday	1:00 PM	Susan Mayer, MHSPT	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Summer Session July 8 – Sept 10 Fall Session Oct. 7-Dec. 10	1:00 PM Tuesdays	Brenda Neumann	636-896-0999 x21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lauten- schleger, 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 Healthwise Center 6 Jungermann Circle	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.	Summer session July 11-Sept 12 Fall Session Oct. 7-Dec. 10	2:00 PM Thursdays	Brenda Neumann	636-896-0999 x21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534

APDA-Greater St. Louis Chapter August 2013 LiNK



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APDAGreaterStLouisChapter

Keep up with the latest news, program information, and share articles and photos with Facebook friends.

LIKE US and spread the word!

Mark Your Calendar!

Honoring Dad's Memory on Father's Day



Rebecca Bruchhauser Farris, APDA Board Member

It's the first year I can't wish my dad a happy Father's Day. Last week, during a three hour executive board meeting with the National American Parkinson Disease Association, my mind drifted. I kept wondering how differently our lives and relationships would have been if he hadn't been robbed of

so many good years by Parkinson disease, diagnosed when I was five years old. They say there is no "normal" relationship, but when the caregiver roles are reversed between a dad and his "baby girl," it's not "normal" for anyone until you find yourself thankful for what you do have. I was looking for rare photos of us from before his illness. Like most, he had symptoms for years without a correct diagnosis. I miss my dad, and I hate that we missed sharing our lives together before his health was stolen by an ugly neurological degenerative disease. I can't hug him today, but I can honor his memory by continuing to help APDA to fight for a cure and to ease the burden for caregivers. I suppose that will have to be enough.

August 17

8th annual Hull of a Race, Walk/Run, benefiting the American Parkinson Disease Association, held in downtown Hull, IL, visit www.hullofarace.com

September 14

16th annual Mid-Missouri Parkinson Conference, Caring for the Patient and the Caregiver, Columbia, MO. For more information, contact Patsy and David Dalton @ 573-356-6036

October 1-4

World Parkinson Congress, to be held in Montreal, Canada. For more information and to register to attend, visit www.worldpdcongress.org/

October 14

Focus on Fashion & Philanthropy at the 18th annual auction/ luncheon/fashion show benefiting the American Parkinson Disease Association

November 2-3

There will be an opportunity to learn more about the LSVT BIG program by volunteering to participate in the November 3 afternoon session with newly trained LSVT BIG clinicians. For more information, please visit the LSVT Global website.

November 17, 2:00 PM

Dr. Joel Perlmutter will present, *Why I Am Optimistic and Hopeful-Looking Forward* at his annual Parkinson Education Program. This program will be held at Congregation Shaare Emeth at the corner of Ladue & Ballas Roads in west St. Louis county. His presentation will be followed by a question and answer session, so be sure to bring your questions to this special session.