LiNK

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Greater St. Louis Chapter
Serving Missouri and Southern Illinois

IN THIS ISSUE

APDA Greater St. Louis Chapter
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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.

Be An Advocate!


Debbie Guyer, MA

By definition, an advocate is a "supporter, promoter, campaigner, backer," and that is exactly what we need when you consider that there are 11,238 PD cases among Medicare beneficiaries in Missouri and 23,050 PD cases in Illinois (Willis et al). Of those numbers, 53.5% of PD patients do not see a neurologist in Missouri and 47.4% of PD patients do not see a neurologist in Illinois. This newsletter is distributed to 6,000 people in the bi-state region and another 2,500 across the country outside of our service area. That means we have a lot of work to do to make connections with everyone touched by Parkinson disease, much more than our staff of two can manage.

One of our newest members, Terri, came into my office one Friday morning before Tai Chi with a request. She wondered if I might give her information about PD and the APDA to share with her primary care physician and her neurologist in private practice at a nearby community hospital. "Do you think it would offend them?"

I actually think the APDA and our wonderful Parkinson Resource Center in Chesterfield are best-kept secrets in spite of our efforts to raise awareness, and I welcome patients and family members to advocate on our behalf. A welcome packet containing a handbook, exercise booklet, program and service descriptions, LiNK newsletters, wallet medication card, literature order form, *The Parkinson Journey* DVD, and a note to the physician were given for Terri to deliver during her next office visit. Terri came back to report that her physician readily sends people to the Alzheimer's office, the American Heart Association, the Cancer Society, and MS Society, but had no idea we existed. He was delighted to receive the information for the many Parkinson patients he treats.

John came in to pick up information for his Ophthalmologist with whom he engaged in conversation when he reported changes in his medical condition since his last visit. And when I went in for my annual visit, the discussion with this same physician about Parkinson's and vision problems continued. I can think of no better way to spread the word than when you visit with your physicians. Spread the word with the person standing next to you in the check-out lane at the grocery store or with friends at a party. With the ever-increasing number of individuals being diagnosed with Parkinson disease, don't assume they have found the APDA. They may not be as resourceful as you!

Just the other day, a couple stopped in to see the Center and schedule a PD101 session. He was diagnosed in 2011 at a large Movement Disorder Center here in St. Louis, but had never been told about APDA until they switched to another Movement Disorder Specialist recently. He gave them the LiNK newsletter and told them to call us. The patient's wife called, and a welcome packet was mailed out that same day. They followed up by stopping in to see our exercise class and schedule an individual PD101 for newly diagnosed individuals and their family members. These sessions are available to all patients and families who have been recently diagnosed at many APDA Information & Referral Centers across the country.

We hope you will join the many advocates already working as volunteers for the APDA, spreading the word and making certain that no one feels alone and unconnected. Please visit our website, www.stlapda.org, where you can read about recent news, peruse the archived newsletters from 2007 for information and find a link to another wonderful website. There is so much to learn and so much to do for yourselves and for others, and we appreciate your continued support and your advocacy. ■

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Bend the Curve—Change the Future

Michelle Burack, MD. PhD
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Michelle Burack

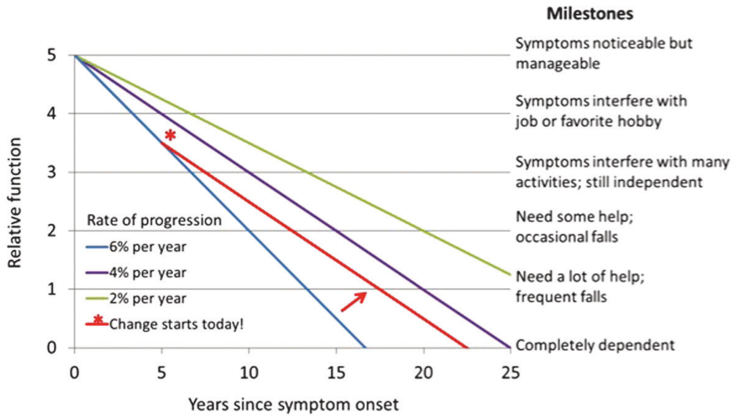
Greetings from Rochester, NY! I moved from St. Louis to Rochester after my movement disorders fellowship with Dr. Perlmutter ended in 2007. I was delighted to hear from Debbie Guyer, who asked me to contribute as a guest author to the St. Louis APDA *LiNK* newsletter. This is an exciting time to be a researcher and physician working with people with Parkinson disease, and we are learning new things every day that can improve quality of life and move us closer to a cure. I want to share what we are learning in a way that is understandable and relevant to YOU, since you are the reason we work so hard to beat this disease.

Our local support group chapter's annual symposium was held in April, and I had the opportunity to hear John Baumann, a motivational speaker who "just happens to have Parkinson disease." His action-oriented, positive perspective, and quirky sense of humor were the highlight of the day. A video of one of his presentations can be found on the internet at http://theinspiringesquire.com.

The transformation John described—the improvement in well-being that came about once he changed his lifestyle—is something that I have observed in my clinical practice many times, but has been hard to "prescribe" effectively for everyone. For some people, just knowing that it is possible to change the future is enough to energize and motivate action. For others, it's not so easy. No matter how it's phrased—"Commit," "Just Do It," "Mind Over Matter," "Whatever it Takes"—it can feel like trying to pull yourself up by your bootstraps.

Fortunately, the rules of gravity do not apply here! Daily choices and mental attitude can have a significant long-term impact on the evolution of the disease. YOU DO have the power to change what happens. No matter what milestone you may have heard about that seems like an inevitable part of your future, it is possible to push those milestones farther into the future through the choices you make today. Researchers are hunting and searching for medication that can change the course of the disease, but you already have access to powerful interventions that can bend the curve.

Everyone's PD progresses differently; some progress more slowly, others more rapidly. There are many different tools that researchers use to measure progression for clinical trials, and different tools show different rates of change per year. It doesn't necessarily progress in smooth linear fashion. So this graph is a rough sketch I created simply to illustrate the following point:



No matter which curve you find yourself on today, you can bend that curve and change the future.

The fundamental principle is "use it or lose it"—physical activity and social engagement are key to keeping brain cells alive, and can even stimulate brain cells to form new connections. Inactivity leads to faster decline not only in the brain, but also erodes mobility, flexibility, and strength through changes in the muscles and joints.

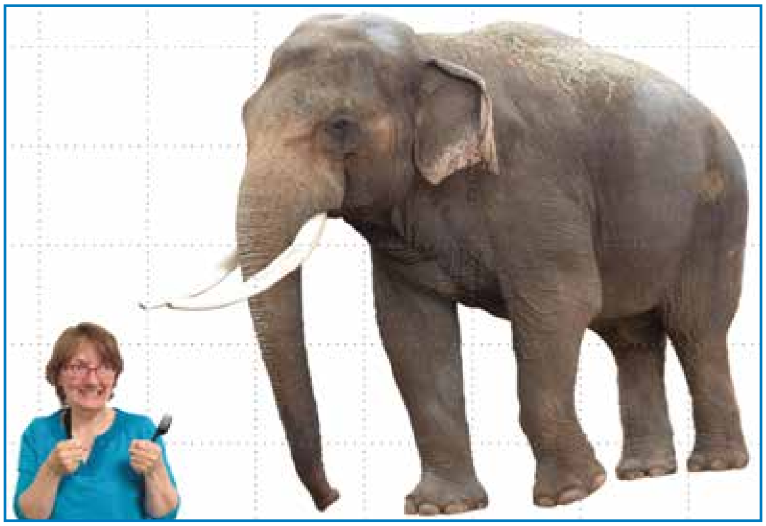
Some common barriers that can make it feel like a struggle against the boot straps:

1. Apathy and depression are common symptoms of PD.

We know that PD can affect the mood circuits in the brain—"it's not just a movement disorder." Sometimes the mood changes are easily recognized as depression, with loss of motivation and interest accompanied by feelings of hopelessness, worthlessness, or sadness. Other times, there can be loss of motivation without the sad hopeless feelings—i.e., apathy without depression.

In studies that looked at mood and motivation symptoms in people with PD, 40% had apathy with depression, 20% had apathy without depression, 15% had depression without apathy, and 25% had neither. Many antidepressants are known to be effective for treatment of depression in PD. In contrast, we don't really know what treatments are most effective for apathy that is not associated with depression, and well-designed research studies will be essential to determine what interventions can help.

Take-home point: If you are experiencing apathy, talk to your provider about whether depression might be at the root of it. Depression is treatable!



How do you eat an elephant?

One bite at a time.

2. Dopamine is important for movement, but it is also important for motivation.

In the movement circuits, dopamine helps the brain decide when to move and when not to move. Without dopamine, the brain decides "don't move" too often, leading to problems with coordinated movements like walking, talking, swallowing, writing, etc.—causing smaller movements, slower movements, fewer movements, and difficulty starting movements.

Dopamine also helps the brain decide at a higher level whether actions are a good idea or a bad idea. In some areas of the brain, dopamine serves as a "reward hormone," helping the brain remember actions that led to something good. Opportunities for similar actions in the future are remembered as a "good idea" that can hopefully lead to similar rewards. (Drugs of abuse like cocaine hijack this reward system, leading to addiction.)

In PD, the dopamine neurons in the movement circuit are usually affected earlier and more severely than dopamine neurons in the "reward" system, resulting in greater changes in movement than in motivation and decision making. However, the dopamine in the reward circuits can also become involved with PD. Using a special type of brain scan, researchers measured dopamine in the brain's reward centers in people with PD, and found that individuals with apathy symptoms had lower dopamine release in the reward centers compared to individuals without apathy symptoms. Other studies have found that on average, individuals with apathy take lower doses of PD medication than individuals without apathy. Apathy can also sometimes emerge when medications are lowered after deep brain stimulation surgery. This all suggests that apathy might respond to increased dopamine-replacement medication. However, too much PD medication in the reward circuits can lead to altered decision making and risky behavior in some individuals. It is important to work closely with your provider to make sure your dose of medication is optimally balanced to maximize symptom control while minimizing side effects.

Take-home point: If you lack energy and motivation to push back against PD, talk to your provider about whether your PD medication dose is adequate.

3. Logistics can sometimes seem complicated.

Compared to swallowing a pill, exercise takes investment of significant time and energy. Some types of exercise require transportation to access the equipment or facilities needed to do it. Thinking about these logistics can become so overwhelming that a miracle pill seems easier. But every day that goes by is a lost opportunity to bend that curve. Don't wait. Just like retirement savings, you lose the cumulative benefit of "compound interest" if you don't start early. You don't have to go from zero to 60 in a day. Start simple. How do you eat an elephant? (One bite at a time.)

If your daily activity is zero minutes, start with 5 minutes. If it is 5 minutes, celebrate! and then make it 10. Slow and steady wins the race, but only if you take that first step off the starting line. You can do it!

If you're already exercising an hour a day, bravo! You can still benefit from trying to push the intensity a little harder. Beyond the personal anecdotes like John Baumann's, there is scientific evidence that forced exercise, i.e., pushing a little bit beyond what you think you can do leads to global improvements in PD.

Take-home points:

- Start today. Every day adds up to a difference down the road.
- Start small, and build up gradually.
- Choose something that you will actually do on a regular basis. It doesn't have to be fancy. A simple home exercise program that you do every day is going to pay off much more than an elaborate exercise routine you only get around to doing once a month.
- Pushing yourself just a little harder may create new pathways in the brain to slow down the disease.
- Find a friend to exercise with. ■

Beating Caregiver Guilt

Terri Hosto, MSW, LCSW, Kirkwood "Movers and Shakers" Support Group Facilitator

"Guilt is the gift that keeps on giving." This quote is credited to the American satirist Erma Bombeck. With wit and humor she chronicled the trials and tribulations of family life in books and syndicated newspaper columns. In her writings, she was able to make light of difficult family situations and laugh about them with her readers. Funny how certain emotions, like guilt, are universally shared, yet rarely talked about. Perhaps this is why guilt is a favorite topic of psychologists and other mental health experts, although family caregivers arguably are the real experts on the topic of guilt!

Studies of family caregivers have shown strong associations between guilt and depression. Physical signs of guilt may include tension in one's voice, unexplained pangs of pain, pressure on one's shoulders, or a heavy feeling in the chest. Fatigue, difficulty concentrating, lack of pleasure, sleep disturbances and appetite changes—all of which are signs of depression—often accompany feelings of guilt. When left unmanaged, guilt and depression can become debilitating and negatively affect the health and well-being of the caregiver.

If you are a caregiver for a loved one, then you probably have experienced recurrent feelings of guilt along your caregiving journey. Guilt is an emotional state that arises when your thoughts and behaviors are not consistent with your values and beliefs. For example, family caregivers often feel guilty because they think that they should be doing *more* to help the person for whom they are caring, or feel that they could do a *better* job. This type of guilt arises when you feel that you haven't measured up to your own expectations—even though you probably wouldn't hold anyone else to the same impossible high standard!

Admittedly, you have probably made mistakes that you wish you could undo … perhaps you failed to do things you feel you *"shoulda"* done … or maybe there were situations that you think you *"coulda"* handled differently … or possibly you wish you *"woulda"* not said some unpleasant things that you did. When you hold onto "shoulds, coulds and woulds," guilt can spill over and cause you to emotionally beat yourself up for supposed wrongs.

The truth is that as a caregiver, you likely are a nurturing and selfless individual. You think of others first, before ever considering your own needs. You do all that you can to meet the needs, wants and desires of the person you are providing care. This self-sacrificing quality, however, may trigger guilt feelings inside of you. Guilt can seep in if you believe that you aren't satisfactorily devoting time to others in your life and fulfilling responsibilities you have to extended family, friends, work, or the community. You also may feel guilty when you take time for your own needs and even find it difficult to relax because you constantly worry about your loved one. Too many demands on your time, energy and personal resources can foster feelings of helplessness and caregiver guilt, which can lead to burnout.

The caregiving experience evokes an array of emotions—many of which are undeniably negative. Getting angry and losing patience with the person for whom you are caring. Feeling resentful at having to put your own needs, wants and desires second. Feeling helpless when you think of the seemingly endless caregiving tasks ahead of you. Worrying about the future. Feeling overcome by a general sense of inadequacy when you realize that despite your best efforts, your loved one continues to decline. Recurrent thoughts like these can dominate a caregiver's mind and exacerbate feelings of guilt.

Guilt can thwart communication and erode relationships between you, the person you are caring for and significant others in your support system. For instance, you may communicate to others that you are managing everything that comes your way, when in reality you are feeling overwhelmed and need help! You are the person everyone else relies on, not only to do the tasks of caregiving, but also to keep them informed. Yet you won't ask for help. Caregivers without assistance tend to experience the highest rates of burnout.

How do you get off this merry-go-round of guilt and avoid caregiver burnout? First, it is important to get in touch with your thoughts and feelings about your caregiving situation. Do not be ashamed if you find that you harbor some negative emotions. Instead, share them with someone who will listen without judging you. You may find it helpful to speak with a professionally trained counselor. Also consider seeking out other caregivers who are dealing with similar circumstances, perhaps by joining a caregiver support group. Support groups can offer enormous relief by providing an outlet for you to safely vent your feelings and frustrations. Most importantly, understand that your negative feelings and guilt won't go away if you simply ignore them. Working through them can be very cathartic and healing.

Secondly, allow yourself to be less than perfect and learn from mistakes made. You know you want the very best for your loved one; but like everyone else, you have limitations and shortcomings. Accept that there will be times and situations where you fail to meet your own self-imposed standard of care.

There will be ups and downs along the caregiving journey. When you get that gnawing feeling that you've let yourself and others down, it's time for you to review and adjust your expectations. Learn to let go and tolerate things that might not get done perfectly.

Also learn to appreciate and value your work as a caregiver. Make a list of what you do for your loved one, such as prepare meals, run errands, pay bills, assist with personal care, accompany to medical appointments, plan activities that your loved one enjoys, etc. Be sure to include all the positive qualities you bring to the caregiver role, such as being dependable, attentive, careful, knowledgeable, committed, etc. When you look at your list, you'll likely see that the things you do to care for your loved one far outweigh any omissions and failures. This new awareness may help you draw strength and encouragement from your hard work and caregiving efforts. Find positive affirmations of your worthiness to replace negative thoughts and feelings.

Next, make a list of what you do to care for yourself. You'll likely find a shortfall on your side of the ledger. How do you balance meeting your own needs with the needs of your loved one? Even though there may not seem to be enough hours in a day to devote time to self-care, it is essential that you take time to look after yourself. This requires establishing limits on your time and energy. If you are physically and/or mentally stressed, then you can't expect to be at your best for your loved one who depends on you. Instead, the care you give may reflect the tension and weariness you are feeling rather than compassion and comfort. Learn to prioritize your daily tasks to more realistically match your available time and energy. Divide your day into the things you *must do* and the things you would like to do. Be sure to include time for your own self-care—even if it is not proportional to the amount or hours of care given to your loved one.

Self-care involves maintaining a healthy lifestyle (through proper nutrition, regular exercise, adequate rest), participating in activities you find meaningful and personally enjoy, staying connected to family and friends, and having some time away from caregiving. Taking breaks from the demands and duties of caregiving is vital to your well-being. This is called "respite," and a variety of programs are available to provide short periods of relief from caregiving, including in-home companion services and facility-based activity programs. Periods of respite can help restore your physical energy as well as provide mental relief from the worries and concerns of caregiving. Even when you can't get away physically, there are various ways you can take a mental break, such as absorbing yourself in a good book, immersing yourself in your favorite music, using deep breathing exercises and relaxation, or taking a long hot bath. Taking steps like these can help reduce the stress and guilt of caregiving and ensure your well-being. When you reach a healthy balance, you become a more capable and effective caregiver and your loved one is all the more better for it. ■

FOCUS on Fashion and Philanthropy

The 19th Annual APDA Fashion Show, Luncheon and Auction

October 13, 2014

We're excited to bring you another delightful afternoon of fashion, delicious food and gifts from a silent auction filled with tastes of our town restaurant gift cards/certificates and one-of-a-kind items. Proceeds from this event will be used to support APDA's dual mission – to ease the burden and find the cure by expanding patient programs and services to improve quality of life for individuals and family members and funding promising Parkinson research, which seeks to further identify causes and ultimately find a cure for Parkinson disease.

Invite your family, friends and neighbors!

We are thrilled to have Victoria Babu from 1380 The Woman radio and Kevin Steincross from Fox 2 KTVI-TV as our Masters of Ceremonies and to present fall fashions from some of St. Louis's finest boutiques.

Doors open for the silent auction and wine reception 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 13 at the Sheraton Westport Chalet. The cost will remain $65 per guest.

How can you help? Please consider becoming a sponsor. As a sponsor, you or your business will receive prominent placement in our program and on signage at the event, plus special seating at the fashion show. In addition, your name will be featured in the November **LiNK** newsletter distributed to over 8,500 homes and businesses across Missouri and Illinois. Sponsorships begin at $500 with many levels to appeal to any supporter.

For more information about the fashion show and sponsorships, visit our website at **www.stlapda.org** or call the APDA office at 314-362-3299. If you haven't received an invitation in the past and would like to receive one this year, please send an email to **guyerd@neuro.wustl.edu** or give us a call. We'll gladly include you on our guest list! We hope you, your family and friends will join us to make this year's event another "fashionable" success! ■

End of Life Issues in Parkinson Disease

Martha Nance, MD, Medical Director, Struthers Parkinson's Center

Dr. Martha Nance

We don't like to talk about it, but everyone with Parkinson disease wonders about it, worries about it, tries not to think about it: dying and death. How do people with Parkinson disease die, and if we can't stop it, what can we do to make it easier or more comfortable?

Many people with Parkinson disease (PD) die with Parkinson disease, rather than dying of Parkinson disease. For those people, Parkinson's is a complicating factor, leading to greater immobility or more confusion, but may not be the primary concern during the dying process.

If a person is so fortunate as to have no other life-threatening health problems, and disability, dying, and death are related to PD, several scenarios can occur.

Some people have trouble primarily with mobility, going from cane to walker to wheelchair despite appropriate treatment, and develop complications of immobility—weakness, depression, loss of social interaction, weight loss, and general slow decline. This gradual decline is often punctuated by serious or life-threatening events such as bladder or lung infections, which may lead to a stepwise decline in function, or could be a terminal event.

A special note should be made about falls at this stage of Parkinson disease. Although some falls can be minor, and some people recover surprisingly well from a broken wrist or broken hip, an elderly person with long-standing Parkinson disease who has a hip fracture will likely experience a permanent decline in function, and some never recover.

Some people with PD develop significant changes in mental processing, or dementia. Whether the doctor uses the term "Lewy body disease," "Parkinson disease dementia," "Alzheimer's disease," or simply the more general term "dementia," this aspect of Parkinson disease complicates things. People who have dementia may have difficulty remembering to take their medications, forget that they have mobility issues and are thus more likely to fall, and may later become less able to attend to their own personal needs. The decline is more rapid in people with Parkinson disease who have dementia than in those who do not, and complications and death come sooner.

So—what can we do about all this? Long before any of these things happen, we should all have an "Advance Directives" document, or "Living Will" that will help to guide our families should we become gradually or abruptly unable to speak for ourselves at any stage of life. As Parkinson disease progresses, it is useful to revisit that document periodically (at an age ending in 0 or 5, after a hospitalization, before a planned surgery, for instance), to make sure that it reflects your current views, which may change or evolve as you age.

Think about whether you (or the loved one with PD whom you are supporting or caring for) have any of these features that could suggest the late stages of Parkinson disease:

The presence of Parkinson disease for over 20 years:

- a person who is over 80 years old
- a person who is mostly or fully restricted to a wheelchair
- a person who has one or more serious chronic or acute health problems in addition to Parkinson disease
- weight loss despite aggressive attempts to improve nutritional intake
- repeated hospitalizations
- the need for nursing home placement
- the presence of dementia

The more of these features that are present, the more ominous the situation. Ask the doctor what he thinks the future holds. Worsening disability, and even dying or death, should not come as a surprise in a slowly progressive disease like Parkinson disease.

We have now described several general scenarios that might herald the end of life in a person with PD, and the thought of preparing in advance for this time. But what should the doctor, person with Parkinson disease, or family DO during the dying process to make things easier or better?

The first thing is for everyone involved to be clear about the goals of care. If the goal is to prolong life aggressively, the treatment approach will be different than if the goal is to be comfortable, free of pain, and surrounded by family. In the latter case, all treatments or changes in treatment should be helping to move toward that goal. Some people with PD who are no longer able to walk (whether due to Parkinson disease, complications of a fracture, or some other cause) may not need as much "Parkinson's medicine" any more. It may be possible to taper down or off selegiline, entacapone, pramipexole, or even levodopa. It may also be possible to stop a number of other drugs at that point, too—cholesterol medicine, vitamins, etc. Some people, particularly those with tremor or anxiety as prominent Parkinson's-related symptoms, may not be able to taper down their Parkinson's medications. Some Parkinson's medicines can be given by melt-in-the-mouth pills (levodopa in the form of Parcopa; selegiline in the form of Zelapar), and by skin patch (rotigotine) if it is difficult for a person to swallow pills.

Some medications that the doctor might want to use have the potential to worsen the motor symptoms of Parkinson disease. While this may or may not matter to a person who is immobile or unaware, the family and doctor should be aware of this possibility, and make a judgment in each case whether the drug is more beneficial or more harmful. This list of medications includes most of the neuroleptic (anti-hallucination) drugs, such as haloperidol, risperidone, and olanzapine (quetiapine is generally the least likely of the neuroleptic drugs to cause trouble); compazine (used to treat nausea); and metoclopramide (used for nausea or poor intestinal motility).

People with PD are often more sensitive to the cognitive or mental side effects of medications such as narcotics. This does not mean that these drugs shouldn't be used, but they should be

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And Parkinson's Makes Three

Peggy van Hulsteyn, author and individual with PD

Peggy
van Hulsteyn

Parkinson disease is the unwanted third party in my marriage: he's the elephant in the room, the man who came to dinner, and the worst house guest ever, all rolled into one. How has this insidious intruder affected my wedded bliss? Initially his shenanigans did indeed cause havoc in our household. This spook, who I cynically call the Parkinson's gremlin, was determined to put a "foreclosure" sign on our lives. To be sure, he has huffed and he has puffed, and yet our house still stands. He is a formidable opponent, but we are stronger than he is. My husband, David, and I figure that there are two of us but only one of him, so we will prevail!

A comforting and powerful way to view this relentless battle is to realize that those of us with Parkinson's are part of a global community and that we are not alone. When we recently attended the 2013 World Parkinson's Congress (WPC) in Montreal, there was an inherent sense of community and hope. During the welcoming address, Bob Kuhn, a WPC Ambassador and a person with Parkinson's, encapsulated this feeling of optimism with the simple, yet profound observation: "The biggest difference between illness and wellness is that illness starts with the word "i" and Wellness starts with the word "We."

David and I are the "We," with a capital W, in this battle and Parkinson's disease is the insignificant, lower case "i."

The only thing that my husband and Parkinson disease have in common is that they both entered my life quickly and unexpectedly and caught me by surprise. But I am getting ahead of myself, so let me start at the very beginning—a very good place to start. David and I met on a blind date, six months after I had pulled the plug on the "wedding of the year" to my high school sweetheart. The Midwest circa 1968 was an uncompromising place where your word was your bond, so when I phoned the printer to order "The wedding has been canceled" cards, he informed me in no uncertain terms that "In Indiana, if we say we are going to get married, we get married, no matter what!"

I fled back to my home and job in cosmopolitan Atlanta, where I worked as a movie publicist. My friends there, much more understanding and supportive, took me under their wings, offering to play matchmaker. "I'm through with love," I declared defiantly. "From now on, there will only be superficial dating, uninvolved fun and gourmet food." So, when Carol, a childhood friend, told me she wanted to fix me up with a recently divorced physicist who would be passing through town, I agreed reluctantly, thinking there would at least be a free meal. The stats of this mystery man, however, sounded dreary. Physicists are known to be nerds with calculators on their belts; they wear mix-matched socks and their conversations are filled with equations and formulas. What was I thinking? Sighing, I made a dinner reservation at the brand new Hyatt Regency, the current talk of the town. Even if the date turned out to be as dismal as I expected, at least I'd enjoy a delicious repast at this elegant hot spot.

Imagine my surprise when I met David at the airport. He looked nothing like a member of the cast of The Big Bang Theory. Rather, he was a good-looking chap with beautiful curly hair and an engaging smile. His clothes, admittedly, could have come from the physicist ready-to-wear rack, but they were obviously covering a magnificent body. During the drive to the restaurant, I discovered that David was extremely intelligent and that he had a dry wit and a flair for word play. I was delighted to find him a fellow wordsmith, employing language with precision and insight. We stayed up the whole night talking. Giddy with champagne and urbane conversation, our repartee was as sparkling as a Noel Coward play. We were finishing each other's sentences with language inspired by P.G Wodehouse and The Bard. By the time "light in yonder window broke," I had decided that this was the man I was going to marry!

My erstwhile supportive friends in Atlanta had, in the meantime, prepared a list of would-be blind dates for me. "Married?" they scoffed. Had I taken leave of my senses? Before my very eyes, they instantly became a Greek chorus of naysayers: "He's not Jewish." "He's a physicist." "He's divorced with kids." I paid them no heed and instead followed my heart. Reader, I married him! And now here we are, 45 years later.

We began our married life in quirky, delightful Austin, Texas, where David was an assistant professor of Electrical Engineering at the University of Texas and I owned a small, creative advertising agency. I relished being a stepmother and raising David's two children, ages 5 and 9. I apprenticed myself to the cookbooks of Julia Child, mastering the most delicious of the domestic arts, even as I was a passionate advocate for the Women's Movement.

Five years later, we moved to Santa Fe, New Mexico, where David had taken a position as a research scientist at the nearby Los Alamos National Laboratory. My transition, however, wasn't so easy. My "Are-we-there-yet?" personality did not match the laid-back manana style of mellow Santa Fe.

Although a cultural mecca, laden with a rich history of science (birth of the nuclear age) and art (from rock art to pop art, from Aztec to high tech), Santa Fe was the slowest place I'd ever been. I was told by the locals that I suffered from what the Navajos call the "hurry sickness."

I had always planned to write books "someday." With no job market in Santa Fe, I realized that "someday" had arrived and made the enormous professional leap from the adrenaline rush of advertising to the slower, more reflective world of author and teacher. The adjustment was difficult, but, eight books and hundreds of articles later, I am very grateful that I was forced to switch gears. Drawing on my experience, I wrote several books on women in business, then branched into humor pieces, penning articles for local and national publications. When I took on travel writing, David joined me in this pleasant research, and we took long lovely journeys to explore places I had never heard of before. Throughout it all, we were madly in love. Like our first conversation many years earlier, our relationship tripped along with harmony and humor.

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16th Annual APDA Golf Classic Held in Memory of Jack Buck – Another Winner!

This year's APDA Golf Classic in memory of Jack Buck was a record fundraising success with over $110,000 raised for patient services and Parkinson research. We are anticipating receiving even more as matching funds continue to arrive. The event, with the generous assistance of Honorary Chair John Mozeliak, moderator and auctioneer Dan McLaughlin and the Jack Buck family, also served to increase the awareness of Parkinson's in our local community. We're convinced that the weatherman must have a connection to PD, as we had one of the most beautiful spring days at Algonquin Golf Club in Glendale this year!

Our success was attributed to our loyal sponsors, both new and those who continue their support year after year: **CELEBRITY** level sponsors: Moneta Group and Wells Fargo Commercial Banking; **MAJOR** level sponsors: Mark Burkhart and the Community Partnership at Benton Homebuilders; **GOLF CART** sponsors: Barnes-Jewish Hospital and Carol House Furniture; **CONTEST** sponsors: Brinkmann Constructors, Express Scripts and Riverside Furniture; **LUNCH** sponsors: KPMG and Legacy Packaging; **COCKTAIL RECEPTION** sponsors: Budget Billboards, Inc., Steve and Lynn Hurster, Merrill Lynch Wealth Management and the St. Louis Cardinals; **BEVERAGE/SNACK** sponsors: Aspenhome, Centric Group and Gershman Commercial Real Estate; **CADDIE** sponsor: John and Jean Basilico; **DRIVING RANGE** sponsor: Don Carlson; **PRACTICE GREEN** sponsor: The S.E. Farris Law Firm; and **HOLE** sponsors: A.R.T. Furniture, Cooperative Home Care, Larry and Sonya Davis, The Delmar Gardens Family, Duke Realty, Express Scripts, Fastsigns of Bridgeton, Flexsteel Industries, Grey Eagle Distributors, Guarantee Electrical, Keith and Cindi Guller, Henges Interiors, Horner & Shifrin, Inc., Husch Blackwell, Kodner Gallery, Mark and Nancy Kodner, Jim and Jennifer Koman, Maryville University, Miss Elaine, Seeger Toyota Scion (honoring Sue George and Stan Wilensky), Shillington Box Company, Serta Mattress Company, Jack Strosnider and Universal Furniture International.


Dennis O'Leary


John Mozeliak, Bill Biermann, Bill Taylor, Dan Thies

CHARITABLE CONTRIBUTIONS arrived in generous proportions from: Tom Eidelman, Paul Gallant, Suzanne Hurster Wood, Ron and Sharyn Kessler, Mark and Nancy Kodner, Nancy Lieberman, Matter Family Office, Janet Noble, Reitz & Jens, Inc., Bert Schott, Terri Taylor, Cassidy Turley and Marjorie and Kent White.

AUCTION ITEMS were donated by Autohaus BMW, Continuum, Golf Discount of St. Louis, Thomas E. Kramer, Dan McLaughlin, Don Marquess, John Mozeliak and the St. Louis Cardinals, St. Louis Blues, Valued Pharmacy Services (Mike Rogers) and Grant Washburn.


Dan McLaughlin and John Mozeliak


Monsignor Ullrich, John Stievens, John Basilico, Mark & Pat Burkhart, Terry Higgins


Brad Racette, Nick & Lauren Uhl, Jim O'Leary, Susan & Dennis O'Leary

Caps off to these special **VENDORS** who helped make the event a success: Autohaus BMW for the hole-in-one car and special sleeves of golf balls for our golfers; Crown Trophy for the crystal golf awards (in memory of Shale Marshal Rifkin, MD); Fastsigns of Bridgeton (Barry Roufa) for the wonderful signage; Larry Glenn and Zach Dalin for their professional photography services day and evening; and Dan McLaughlin and John Mozeliak for media/marketing leading up to the sold-out event.

It does indeed "take a village" – special recognition to our hard-working volunteers under the direction of **Golf Committee** Chairman, Matt LaMartina, and committee members John Basilico, Dwight Rasmussen, Barry Roufa, Dave Sadler, Matt Schumacher and Grant Washburn; as well as Kay Bruchhauser, Ann Cook, Rebecca B. Farris, Bob Goldsticker, Karl Guyer, Barb Koch, Benjy and Joyce Levin, Laura Pupillo, Dot and Dwight Rasmussen, 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 community day of service: Matt Black, Patty Boehm, John Brandt, Antonio Cirami, Sarah Krantz, Eric McFarland, Dave Lucido, Jeremy Medley, Andy Pursifull and Mary Lou Sullivan.

We can't forget to thank our 144 golfers who had a great day on the greens, bidding on many wonderful auction items, enjoying the **Question-and-Answer** session with John Mozeliak and Dan McLaughlin, and feasting on the dinner served by wait staff at Algonquin. Auctioneer-extraordinaire 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 Matt Carpenter, Stan Musial, Alex Steen and Michael Wacha; the opportunity to throw out the first pitch, dinner in the Cardinal Club and 4 field box seats donated by the St. Louis Cardinals; and the opportunity to throw out the first pitch, 4 tickets to a Cardinals game and access to the broadcast booth donated by Dan. Additional live auction items included 4 tickets in the green seats for a Cardinals game and a BMW Carbon Racer Bike donated by Autohaus. **Silent Auction** gifts included: sets of Cardinal baseball tickets; signed baseballs from Yadier Molina, Trevor Rosenthal and Adam Wainwright; signed bat from Matt Holliday; a 2013-14 St. Louis Blues team souvenir stick; signed photos of St. Louis Blues players and a foursome of golf with lunch at Algonquin Golf Club.


Therese Washburn, Earl Wims, Jennifer & Tim Potter, Loren Wims, Brant Beste, Dan McLaughlin, Grant Washburn


Angie Fox, Annemarie & Matt Schumacher, Rich Chrismer, Addie Tompkins, Chris Theole, Ted Hume, Jim Gwinner


Paul Kalsbeek, Jim Whalen

The evening was capped off by an emotional and meaningful testimonial from Dennis O'Leary who has had Parkinson's for over two decades and was featured on the cover of our February **LiNK** newsletter with his son, John. We appreciate Denny sharing his inspirational message of hope and determination with the audience. As a result of his moving story over, $11,000 was collected during the **Fund-a-Need** portion of the evening from generous individuals/couples present: Michael J. Berg, Dave Butler, Robert Cohen, David Elhoffer, Ted Hume, Alan and Marty Lemley, John McCulloch, Paul and Mary Mercurio, Gary Muenster, Dennis O'Leary, Steven and Susan Ostrander, Dot and Dwight Rasmussen, Bill and Shari Reller, Dave and Christine Sadler, Rich Schindehette, Doug and Susie Schoen, Kurt Schoen, Matt and Annemarie Schumacher, Scottrade, Rich Smith, John Stieven, Magnus Tannfeld, Douglas and Susan Warden, Grant and Therese Washburn, Earl Wims, Loren Wims, Jeff Wist and Marty Zygmund.


Jim Crews

Please consider volunteering for our golf committee. If you wish to receive an invitation for next year's golf tournament to be held on Monday, May 18, 2015, at Algonquin Golf Club, let us know at 314-362-3299 or e-mail guyerd@neuro.wustl.edu. ■

Saluki Swim Club Swims for Cary

American Parkinson's
OPTIMISM
EVENTS

The Saluki Swim Club conducted a fundraiser in honor of Cary Ann Bailey, a 37-year-old diagnosed with early-onset Parkinson disease two years ago. Cary Ann is a mother of two, Cody (age 17) and Chloe (age 12), and a swim mom living in Du Quoin, Illinois. Cary Ann refuses to give in and recently ran in our GO! St. Louis 5K race, raising over $2,500 in pledges for Parkinson research. Members of the Saluki Swim Club refuse to give up either, conducting a swim-a-thon and raising $4,550 to fund Parkinson patient services in our local communities and promising Parkinson research. Teen swimmers Eleni Robinson and Kelsie Walker were passionate about hosting this event. Eleni designed shirts and her father's company, J & L Robinson Construction Company, donated the shirts so all the proceeds would go to the Greater St. Louis Chapter of the American Parkinson Disease Association, serving the state of Missouri and southern Illinois. Approximately 60 swimmers participated in the water, with 40 members collecting pledges for their swim. Cary wants to inspire others, and "Swim for Cary-Swim for the Cure" motivated these swimmers to make every lap count. ■

Tributes & Donations 4/1/14 – 6/30/14

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 Greater St. Louis APDA on the help & kindness given to step-father, Walter F. Heuer
Daniel R. Evans, Jr.

Cathy & Randy Arst on son, Gregg's, wedding
Sue & Phil Schreiber

Speedy Recovery John Basilico
Debbie & Karl Guyer

David & Gail Berwald 50th Anniversary
Pam & Jerry Brown

Barbara Binder 70th Birthday
Roberta Hayman

Susan Buse school board election
Gail, Larry & Alyssa Glenn

David & Patsy Dalton – Heroes in Healthcare Award
Debbie Guyer

Connie Dankmyer
Tom & Laura Moran

Holly Evans 10th Anniversary as Facilitator in APDA St. Peters Exercise Group
Earl & Cathy Adkison
Dale & Norma Plank

Speedy recovery Don Goldman
Gail, Larry & Alyssa Glenn

Jon Goldman Birthday
Gail, Larry & Alyssa Glenn

Ralph Goldsticker
Larry & Andi Goldsticker & Family

M/M Bob Gunby's Party
Sid & Fran Axelbaum

Debbie & Karl Guyer 37th Anniversary
Jeff & Debbie Dalin

Kristy Howell
Jennah Bartels

Morris Joftus retirement
Art & Fran Poger

Nancy Klein 70th Birthday
Joan & Raymond Kasparian
Andrew M. Klein III

Lynne & Jerry Krug 50th Anniversary
Beverly & Jerry Silverman

Carol Landgraff
James Landgraff

Rita Levis Special Birthday
Mr. & Mrs. John Isaacs III
Ann Lux

Speedy recovery Joel Levy
Pam & Jerry Brown

Gloria Licameli 90th Birthday
Emilia & Thomas Licameli

In appreciation of Melinda Mierek
Jennah Bartels

Judy Pass 70th Birthday
Harlan & Barbara Floom
Roberta Hayman

Ann Byrum Ritter Pioneer Leadership Award
Debbie Guyer
Missouri Alliance for Home Care

Mike Scheller
Arnold Goldman

Elizabeth Schweizer 90th Birthday
Ralph Goldsticker

Martin Shrader
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Judy Ugalde

Speedy recovery Jack Strosnider
Karl & Debbie Guyer

Jim Sutton
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Terri & Bill Taylor Anniversary
Roz Gad

Speedy recovery Tom Traber
Jack Strosnider

Bob & Kathleen Voss 60th Anniversary
Sheila & Gary Diepenbrock
Marty & Debbie Voss

Janie Walter Birthday
Kay Bruchhauser

Stacy & Lenny Zeid
Gail, Larry & Alyssa Glenn

Remembering

Glenn Amster's father
Ken & Mary Shapiro

Tommy "Tom" Baldwin
Diane Ottolini

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WAJA Funding Tremble Clefs and Parkinson Disease Family Conference

The Greater St. Louis Chapter of the APDA has recently been awarded a $5,500 grant from the Women's Auxiliary for the Jewish Aged (WAJA) to help offset the costs of the new Tremble Clefs program and a symposium to be held in 2014 for care partners and adult children of people with Parkinson disease. The main purpose of the WAJA is to assist 501(c)(3) senior living facilities and provide service to the Jewish elderly in the community-at-large. Our Tremble Clefs program is open to all interested individuals. Tremble Clefs is a weekly program led by a music therapist that uses vocal exercises, singing, and playing musical instruments to help address voice and communication challenges faced by people with Parkinson's. The symposium will be a family conference for care partners and adult children of people with Parkinson's who find themselves in new roles as they care for their loved ones. Three break-out sessions will be offered in addition to a special keynote speaker. We thank the Women's Auxiliary for the Jewish Aged for their generosity and support of the Greater St. Louis Parkinson community.

Kahn Foundation Grant To Fund Family Symposium

The Greater St. Louis Chapter of the APDA has recently been awarded a $5,000 grant from the Kahn Foundation of Temple Israel to partially fund our Family Symposium to be held on Sunday, October 26, at Congregation Shaare Emeth. Dr. Paul Short, neuropsychologist, will be the keynote speaker in addition to facilitating a morning support group trainer session and a break-out session following his keynote address. Look for your invitation to arrive in the mail in September.

Please note that this conference is made available by grants received from the Kahn Foundation, the WAJA, and the generosity of board member, Melinda Mierek. ■

End of Life Issues

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used thoughtfully, with an assessment of whether they are having the desired effect (usually reduction of pain or anxiety) or any side effects.

It can be very helpful in the late stages of PD to involve experts specializing in the late stages of life, the hospice team. This team of doctors and nurses can help to sharpen the focus of care onto quality of life, comfort, family involvement, and dignity, and away from the use of invasive tests and procedures and complex medication regimens to diagnose and solve medical challenges. Ask your doctor whether hospice care would be appropriate at your stage of Parkinson disease. The hospice team may want to work with, or at least to communicate with, your neurologist on treatment decisions that are related to the Parkinson's.

Comfort takes many forms, most of which are more accessible to the family than to the health care team. A favorite pillow or blanket, beloved pet, visits from family, enjoyable music, food, or clothes may mean more to a person in the terminal stages of life than one more pill or a different kind of wheelchair or walker. Acknowledging that a person is dying permits a family to be prepared, and even to celebrate the person's life with them in a way that is comfortable, meaningful, and at times even beautiful.

In summary, although dying and death are not anyone's favorite things to think about, a little bit of planning can make them less frightening and less burdensome for you and the family and health professionals who will be beside you at this stage of your life. This will, in turn, allow you to LIVE more comfortably! ■

Article appeared in the Minnesota Messenger, *spring 2014 edition and is reprinted with permission from the Minnesota APDA Information & Referral Center.*

Another resource worth investigating is a pamphlet called "Five Wishes," a living will to help start and structure important conversations about care in times of serious illness. One of our Chapter members recommended we obtain this resource. You can preview a sample online at **www.agingwithdignity.org** or stop by our Parkinson Resource Center in Chesterfield where you can view sample copies in our library. They may also be ordered online directly from the web site noted above.

And Parkinson's Makes Three

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In 2000, though, I started to notice a strange assortment of nagging annoyances. My voice, never loud to begin with, now took forced effort to project, a growing problem when I was delivering speeches and conducting workshops. My left arm lagged when I walked, out of synch with the rest of my gait. But when I started losing weight for no perceivable reason, my confounded doctor referred me to a neurologist. My central nervous system was on Red Alert when we showed up for the appointment. Independent research on my symptoms had posed a wealth of unsavory possibilities, and I was torn between suspense and a desperate desire to hide under the bed with my cat. David sat beside me, calmly holding my hand until we were ushered into the doctor's office. With a bedside manner as cold and sterile as her instruments, the neurologist ran me through a battery of coordination tests before pronouncing in a monotone voice, "You have Parkinson disease." I was shocked into silence. David, ever so staunch and cheery, was stunned. Moments after delivering this life-changing diagnosis, the honorable doctor informed us that she had a hospital board meeting to attend, and we would have to leave. I literally felt like The Little Match Girl who was hurled out into the snow.

The voyage on the S. S. Parkinson's is clearly not the journey we signed up for, but David has been by my side every step of the way. PD is not a welcome guest in our relationship, but David and I constantly remind each other that our mantra will always be "there are two of us but only one of him, so we will prevail." During the 13 years since my diagnosis, life has definitely been difficult, and at times, felt impossible. This unwanted third party of a disease has made itself at home in our lives, and with each progressing symptom it has educated us, not only about the maddening, unpredictable nature of Parkinson disease, but also about each other. I have gradually learned to surrender my fierce independence, allowing myself to be vulnerable in ways I would never have dreamed of before.

And David, considerate husband that he is, has risen to the challenge. His help and perspective have daily provided shelter and guidance. Administering medications to try to balance the wildly fluctuating levels of dopamine in a PD patient is a guessing game and a gamble, but at least I have a backer. David's methodical, scientifically trained mind is much better at tracking the never-ending schedule of prescriptions I must take. And, when I am mystified by my own symptoms, he can tell, by a single glance at my face, whether or not I'm over-medicated.

Our relationship has adjusted to incorporate the work of managing my symptoms, but we haven't been overcome by this task. We still enjoy romantic dates and visits with family and a circle of diverse and loyal friends. Our love of travel inspired us to take a transatlantic voyage aboard the *Queen Mary 2* last year. I am engrossed in the various projects that make up my thriving writing career, and have recently celebrated the release of a book on yoga for people with Parkinson's. David has shrugged off his paltry attempt at retirement and parlayed his 40-year love of folk dancing into developing a scientific study on the myriad benefits of folk dancing for those with PD.

Obviously, Parkinson disease has changed and revised our perspectives, both in the intimacy of our relationship and in our public lives. PD has provided writing and scientific material we would have never otherwise tackled. But it has never disempowered us and in its way, has even united us in a common focus. That sharing of focus has proven essential in keeping our relationship vital. I look at David and see not only my love, but a comrade in arms. As Antoine de Saint Exupery wrote, "Love does not exist in gazing at each other, but looking outward in the same direction." ■

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, check our website, **www.stlapda.org**, or 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 Nancy Rapp	636-532-6504 636-537-3761
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	573-356-6036
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	Joe Vernon	314-614-0182
Creve Coeur	St. Louis	Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl.,CLI Rm. 419	3rd Tuesday	6:30 PM	Doug Schroeder	314-306-4516
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Sara Dee	636-931-7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
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 David Dalton	573-356-6036 573-434-4569
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573-785-6222 855-444-7276 573-776-9355
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak	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

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Missouri Support Group Calendar

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	2nd Thursday	2:00 PM	Randi Newsom, RN, BSN	417-820-3157
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

Illinois Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, **www.stlapda.org**, or 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
Alton	Madison	Senior Services Plus 2603 N. Rodgers Ave.	2nd Tuesday	9:30 AM	Kim Campbell	618-465-3298 x146
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	John Kileen	217-620-8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Nancy Goodson Rich Rogier Jeanette Kowalski	618-670-7707 618-288-3297 618-288-9843
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut–Meeting Room 2	1st Wednesday Apr.-June, Aug.-Sept.	6:00 PM	Karen Ladd	217-243-4904
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
Springfield	Sangamon	**St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C**	3rd Sunday	2:00 PM	**Wendy White-Mitter, RN**	**217-544-6464 x47756**

Exercise Classes

The APDA now offers 15 exercise classes that meet weekly in the Greater St. Louis area. Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our patient services funding comes from donations and is limited, so we encourage those who wish to attend multiple classes to make a $5 per week donation. This minimal donation helps us to defray the cost of the classes which run around $10 per person to cover the instructors' salaries, room rentals, and equipment. This donation request is on an honor system, and we don't turn anyone away from attending as many classes as they choose. To make a donation for exercise classes, use the blue envelope in your newsletter and note that it is for exercise class. Many people choose to pay quarterly to reduce the number of checks they write each month. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our patients.

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. Check our website, **www.stlapda.org**, or call to find out any changes since publication.

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 Deslodge Outpatient Center 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Sarah Farnell, OT	314-205-6934
Chesterfield	St. Louis	Friendship Village 15201 Olive Blvd. Friendship Hall-Door #5	Tuesday	1:30 PM	Jessica Andrews	636-733-0780 x7719
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday or Friday	10:00 AM 11:30 AM	Craig Miller	314-362-3299
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Monday	1:30 PM	**Megan Martin, PT**	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	**Summer Session July 7–Sep. 12 Fall Session Oct. 6–Dec. 12**	1:00 PM Tuesdays	Brenda Neumann	636-896-0999 x21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Joplin	Jasper	United Methodist Church 1730 Byers Ave.	Monday	2:15 PM	Nancy Dunaway	417-623-5560
Kirkwood	St. Louis	RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear	Thursday Starting Feb. 6	1:00 PM	Brandon Takacs	618-971-5477
Ladue	St. Louis	Tremble Clefs Singing Salem United Methodist 1200 S. Lindbergh Blvd. Lower Level Choir Room	Saturday	1:30 PM	Linda McNair & Linda Morton	314-362-3299
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 7–Sep. 12 Fall Session Oct. 6–Dec. 12**	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
TO EASE
THE BURDEN
TO FIND THE CURE
American Parkinson Disease Association

Did you know that we produce 9,000 newsletters each quarter? Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list, or if you'd rather receive an electronic version. Just call 314-362-3299 or email guyerd@neuro.wustl.edu to let us know! Thank you in advance for helping us spend our resources wisely!

eScrip

Remember to use your eScrip card every time you check out at Schnucks grocery stores and earn dollars
for APDA Greater St. Louis Chapter!

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

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A Family Conference for Care Partners & Adult Children of Parents with Parkinson Disease

The American Parkinson Disease Association of Greater St. Louis along with generous sponsors, The Kahn Foundation of Temple Israel, the Women's Auxiliary of the Jewish Aged (WAJA), and APDA board member Melinda Mierek are pleased to present A Family Conference for Care Partners & Adult Children of Parents with Parkinson Disease.

Mark your calendars for this unique opportunity!

Sunday, October 26, 2014, 1:30 pm – 4:00 pm

Congregation Shaare Emeth, 11645 Ladue Road, St. Louis, MO 63141(corner of Ladue and Ballas Roads)

Featuring special keynote speaker, Paul Short, PhD, The Parkinson's Coach. Neurocognitive Expert, Behavioral Scientist, and Personal Coach. He will address, *Your Face Is Familiar—Do I Know You?*

Dr. Paul Short provides Internet-based coaching to individuals and families challenged by Parkinson disease and helps develop personalized plans for coping with the disease. Dr. Short's background in neuropsychology allows him to translate many subtle aspects of the disease into plain language that produces practical plans. You can also follow Dr. Short's blogs and videos on his website **http://www.theparkinsonscoach.com**, The Parkinson's Coach and on Twitter @PDpsych.

This family conference will also feature a number of break-out sessions to be announced. Registration will be required. Initial topics under consideration include:

- an elder law attorney discussing disability protection among other things
- dealing with caregiver guilt and role-reversals
- a social worker discussing care options such as home-care, adult day programs, and nursing home and how they are paid for
- cessation of driving

If you have topics which you would like to be discussed during a break-out session, please let us know: **314-362-3299** or by email at **guyerd@neuro.wustl.edu**.