

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

Serving Missouri and Southern Illinois

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American Parkinson Disease Association

#### **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 research.

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. I hope that you derive as much feeling from this piece as I did when I first read it last June. It reminded me of something we all forget (me included)! First and foremost, an individual with Parkinson's is a person: a father, a professor, a husband, and so many other things. They should never be defined by a medical diagnosis, and yet we get so consumed with the disease that we must remind ourselves every day that these individuals are all the wonderful things they were before the diagnosis, and continue to be, whether they are able to communicate in the same fashion, or walk in the same manner, or write as they had before. Take time to remind yourselves: I have Parkinson's but it doesn't have me! And in that spirit, please enjoy this piece Sarah wrote about her father in honor of Father's Day. - Debbie

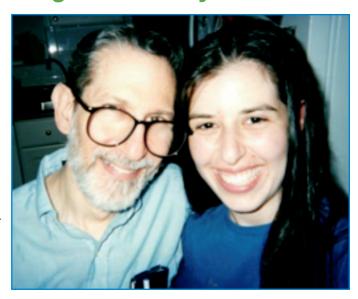
## The Questions I Forgot To Ask My Dad

Sarah Rudolph

It's ironic that most of my childhood memories of my father involve conversation; yet the big family joke is that he never really talked.

hat we mean the tease is that he was never one to open up and share his thoughts and feelings. If we wanted to know how his day of teaching went, or what he liked to do in his spare time, or how he felt when he lost his mother at the age of 14, or whether he believed in Photo courtesy Kvellar.com

God, we would have to pry it out of him. Yet, I was always talking with my father. A philosopher through and through, he challenged my thinking at every turn. Sometimes it was with silly jokes. I torture my own children the way he tortured me, when they announce, "I'm hungry!" and I respond, "Nice to meet you, Hungry. I'm Ima (Hebrew for mother)!" I remember how pleased I was when I first saw the spark in my daughter's eye that indicated



she got it-because I made her stop, think, and understand. Just for a moment. Like my father did for me.

Sometimes it was with philosophy riddles. There was the barber in Seville who "shaves everybody in the town who doesn't shave himself"-and I was supposed to figure out whether the barber shaved himself. On occasion, the ideas went over my head-like that time when I was in fourth grade and

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#### The Questions I Forgot To Ask My Dad

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asked for help with my math homework, and my father began with, "Well, if we let X equal..." I don't remember anything he said beyond that, but I do remember being amused several years later when I finally got to algebra and the sort of abstract thought he had tried to teach me.

I felt like a real daddy's girl when I took philosophy in college and could call him and ask questions or simply share what I was learning, or work with him on my analysis of Descartes. But in all this fatherdaughter intellectual bonding, there was something missing. What I forgot was that my father, too, is human and was once an adolescent. And he was one who had chosen to embrace a religious lifestyle vastly different from the one in which he was raised - all the while studying and teaching multiple areas of philosophy, including those of multiple religions. And I had the gall to think he hadn't struggled with faith and truth, and arrived at some sort of personal conclusions.

My first year as a high school teacher I had a great group of students who liked to get me on tangents into what we called "Philosophy 101." I told them about my father and several latched onto the idea that if they could only speak to him, he would solve all their existential dilemmas. I explained that my father wasn't like that; he enjoyed ideas, but didn't take his philosophy seriously in that kind of personal sense. I didn't think of him as someone who had struggled with faith and reached a happy point of certainty and truth; on the contrary, I was fairly sure he didn't really accept "proof" or "truth" at all. I had the tragic blindness to never ask him what he, personally, believed about anything. To waste the opportunity of years with this brilliant individual, and miss my chance to know what he thought and why?

My father is still with us, yet I find myself speaking of him in past tense because I can't talk to him anymore. Over 20 years of a progressive, nameless, debilitating neurological condition; we have passed the threshold of even pretending there is a coherent conversation to be had. He will occasionally burst out with an audible line that is so classically my father I can't help but laugh and cry. I laugh because he always made me laugh, and because I am

happy to know he is indeed still there. But I cry because those occasional lines are all we get. And I cry because I don't know if he is still fully there but unable to break through the fog of his condition, or if he is simply not all there anymore; and because I don't know which would be worse. I cry because I missed my chance.

Recently, my aunt sent my sister a package of old letters and items. The ultimate treasure in there is the eight-page letter my father wrote his sister when he was a senior in high school. Topics range from a detailed account of his exploits, skipping school (MY father?!) to visit friends and to attend a youth group convention; to references to conversations in which he and his sister apparently shared deep ideological disagreements along with profound love and respect; to allusions to his own beliefs and idealistic ambitions for his future. The letter is quintessentially my father, right down to the part where he claims to be 100 percent sure of something and quickly acknowledges in parentheses that, of course, he is never 100 percent sure of anything. I see him in it, I hear his unique voice, and I also am introduced to a young man I never got to know, who took his philosophical quests as seriously and personally as my students that year, and who was committed to identifying and living the closest approximation to truth he could find. I read it with tears, and laughter. Maybe I didn't completely miss my chance, but there is so much more I want to know.

In honor of Father's Day, I want to thank my aunt for saving and sharing that letter. I want to thank my father, at his age of 16, for having written at such length and with such honesty. I want to kick myself for missing the chances I missed in all those years that I could and did talk to my father. And I want to resolve to talk with my own children as openly and honestly as possible. I want to resolve to save my own adolescent writings, so that even if I find it difficult to be open and honest with them, they can have the chance one day to find those journals and letters and get a window into their mother's heart like I finally got into my father's.

An extended version of this piece originally appeared on **Kveller.com** and is reprinted here with permission.

## **Use It and Keep It!**

## **Helpful Ideas for Those in Rural Areas and Beyond**

Jean Griffard, RN, Facilitator of the Parkinson's Pals Ste. Genevieve Support Group

Living in a rural community can have its drawbacks when it comes to receiving quality care for a disease like Parkinson's. Our location necessitates at least an hour of travel to St Louis to access top-notch medical knowledge and care. However, one benefit of living in a small rural community is the closeness of family and friends, so I decided to try something to maximize those resources.

When Kris Palmer, a member of our Parkinson's Pals support group, read an article in the LiNK about a program for LSVT (Lee Silverman Voice Treatment) graduates which met every three months in St Louis, she was interested in attending such a session. Kris had completed the LSVT training, but since she lives alone, she felt the need for more encouragement to practice her newly learned SPEAK LOUD techniques. Since Kris had traveled an hour to Desloge to receive her LSVT training from LSVT-certified Speech Pathologist, Kathryn McDowell, she contacted Kathryn to see if there was such a group in that area, because arranging travel to St Louis is a problem for Kris, as it is for many people with Parkinson's. There was no such program in Desloge, so Kris and I began to put our heads together and brainstorm.

The APDA publishes a number of wonderful booklets, among them "Speaking Effectively" and "Be Active." I was first introduced to these booklets via my dad, Clete Huck, who was diagnosed with Parkinson's at age 55. (He passed away in 2009 at age 78.) He received these booklets; we paged through them and saw the helpful hints and exercises, practiced them for a week or two, then life got in the way. The books went into a drawer and were soon forgotten. Like so many things in life, unless a concerted effort is made to incorporate something, it falls by the wayside. This is where the idea of Ste. Genevieve's newest Parkinson's resource came into being. What if we had a meeting every month for people with Parkinson's with the sole purpose of doing the exercises in these books together? We don't have regular access to a Physical

Therapist or Speech Pathologist, but we DO have a group of dedicated and determined people living with Parkinson's and a book to guide us as to what to do. So, armed with these resources, the first meeting of the "Use It and Keep It" support group met on May 22, 2013 at Ste. Genevieve Hospital with five committed members in attendance.

Since my training is as a registered nurse, I explained to the group that although we were going to be doing speech exercises from the "Speaking Effectively" booklet, I am not a Speech Pathologist. And while we were doing exercises from the "Be Active" booklet, neither am I a Physical Therapist. I am taking the role of a family member who encourages the person with Parkinson's to practice using the exercises in these booklets to help maintain function. The Greater St. Louis Chapter sent down a box of booklets, and we were ready to begin.

The timing of the meetings coincided with a caregiver support group in our area sponsored by the Alzheimer's Association. Once again, living in a small community we sometimes have to think outside the box. Caregivers of people with dementia are invited to attend the Alzheimer's Caregiver Support Group. The caregiver support group had been struggling, with only two members attending the meetings. Having our "Use It and Keep It" meeting at the same time allows our Parkinson caregivers to attend the Caregiver Support Group, so now the caregiver support group has continued on page 4

## **Help Us Help You - A New Advocacy Committee Forming**

Dee Jay Hubbard, Ph.D., Caregiver Support Group Facilitator

n spite of our best efforts to be helpful to you and your family member with PD when they are hospitalized or placed in a rehabilitation center, in assisted living, or in a nursing home, we continue to hear about your frustrations. These frustrations stem in part from seeing that they are getting the right medications and that their medications are administered on time. Even though we have tried to help by supplying you with approved medication lists, packets of information about what to do when your loved one is hospitalized, and kits with signs and reminders for the staff, the problems persist.

Even when you stay with your loved one around the clock, you find it difficult, if not impossible, to get their medications administered on time and frequently feel that your attempts to intervene on your loved one's behalf are ignored or even create tension between you and the facility staff. The last thing you want to do is alienate those caring for your loved one. No one knows better than you of the consequences when an individual with

PD does not receive their medications on schedule because you have seen, first hand, what happens when they don't. So it is very unnerving when you see your loved one declining because they are not getting their medications on time and you are unable to get the institution's staff to work with you.

We have been exploring some ideas about how we might help but really want input from you about your first-hand experiences, what the problem(s) are, and what can be done to alleviate them. In other words, we need your help to help us help you. Many of you shared your thoughts during the recent Family Conference for Care Partners and Adult Children of Parents with Parkinson Disease which provided us with a perfect opportunity to get feedback from you concerning this important issue. Please call 314-362-3299 for further information and to volunteer for this new advocacy committee forming. It does indeed take a village!

APDA-Greater St. Louis Chapter February 2015 LiNK

## **Avoid The Dangers Of Dehydration**

If you are thirsty, common sense tells you to get a drink. But dehydration has already begun to set in by the time your brain sends the signal that you need a drink.

Make drinking water a part of your daily routine and you can decrease your risk for dehydration – a potentially very serious condition. Older adults are at a higher risk for dehydration because they may not realize their bodies are suffering from lack of fluids until damage has already begun. Water provides a vehicle for other nutrients called electrolytes. Electrolytes include minerals such as sodium, potassium, and calcium. Water helps disseminate these minerals throughout the body and into blood, tissue, and organs. It is necessary for lubricating joints. It is a huge part of blood and digestive liquids, helps transport nutrients and oxygen throughout the body, and

carries away waste materials. Loss of water can be due to medications, illnesses, inability to move around easily, a diminished sense of thirst, or reduced kidney function.

The signs and symptoms of dehydration often mimic that of a general illness, so it's important to pay attention to early warning signs. Look for lack of sweating, little or no urination (or urine that is dark in color), and sunken eyes. The person may be irritable, confused, have low blood pressure, and/or a rapid heartbeat or fever. Signs of severe dehydration include chronic fatigue and lethargy. Muscles may become weak and there may be muscle cramping. At times, seniors are dependent on caregivers who may not realize that they are not taking in enough fluids. Extreme dehydration warrants immediate medical attention.

Dehydration can also cause confusion and weakness. Look for sudden displays of confusion and/or weakness in an otherwise oriented individual, as they may be experiencing dehydration. Typically, an increase in their fluid intake will relieve these symptoms. However, these two symptoms can be indications of a number of different conditions. So, if the symptoms persist after increasing fluids, you may want to consult a physician to determine if there is another condition presenting itself.

Sometimes people in advanced years who live on their own do not drink enough water or other fluids to maintain their health due to mobility issues. They often don't drink enough, possibly because of faulty regulation of thirst, but also perhaps because of cognitive issues, including dementia. Some of them also find it difficult to regularly get up to go to the bathroom or move around so they may purposely limit the amount of fluid they consume to avoid going to the bathroom very often. Patients who are bedridden experience bedsores more readily when dehydrated than those who are able to get up and move around frequently.

Another reason older adults become dehydrated is sometimes because of their medications. With the various health conditions that develop in the senior years, it is not uncommon for people over the age of 60 to be taking multiple medications, some of which increase urine output. Medications to monitor and control heart disease, hypertension, kidney disease, and liver disease are common diuretic medications prescribed for seniors. While individuals realize that these medications are diuretics, they often overlook the need to add more fluids to their daily diet as they take their prescribed medications, and this causes many of them to become dehydrated.

When older adults are dehydrated, they are more susceptible

to infection. Having physical problems or a disease which makes it hard to drink/ swallow or hold a glass, painful to get up from a chair, painful or exhausting to go to the bathroom, or hard to talk or communicate to someone about their symptoms can all increase the risk for dehydration. Usually, the first symptom of dehydration to present is a dark or malodorous urine. This is closely followed by decrease in urine output and chronic constipation (which is difficult to distinguish from Parkinson disease symptoms). Urinary tract infections could develop over time. When the body is not properly flushing itself of toxins, these toxins can cause infections. So, if the person is not getting enough fluids, they are not voiding the toxins regularly. Another factor in elderly dehydration is the increased risk of contracting illnesses such as a common cold and flu. These illnesses cause fluid loss

that is not easily replenished. Older people often have a reduced sensation of thirst, so it's easier to miss the warning signs that they're dehydrating. These individuals also tend to have lower reserves of fluid in the body, so it may be prudent for the older adults to learn to drink regularly even when not thirsty.



#### **Use It and Keep It!**

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seven members at most meetings. It has definitely been a win/win situation for everyone involved!

The "Use It and Keep It" group has been meeting monthly since May of 2013, and will be celebrating our two year anniversary! One member, Bob, hasn't missed a single meeting! You GO, Bob! The participants feel the meetings are helpful, with an added bonus of increasing camaraderie between the members.

So, to those of you living in rural areas, be creative and use the resources available to you. You may be surprised at what you can accomplish!

# Join Team APDA at the 2015 GO! St. Louis Marathon & Family Fitness Weekend

The Greater St. Louis Chapter of the American Parkinson Disease Association (APDA) is an official charity of the 2015 GO! St. Louis Marathon & Family Fitness Weekend, which takes place the weekend of April 11-12, 2015. Last year we raised \$61,440, placing APDA as the top fundraising charity from among all participating organizations. Our goal for 2015 is to raise \$100,000. One hundred percent of funds raised support Parkinson research deemed as the most promising nationwide by the members of the Scientific

the members of the Scientic Advisory Board of the APDA and also support the APDA Information and Referral Centers located in host institutions across the country, such as the one at Washington University School of Medicine.

Help us raise awareness and find a cure for this chronic and progressive disease by joining Team APDA in one of the GO! St. Louis events as a walker or runner.



gostlouis.org

Saturday April 11, 2015 in Forest Park

5k run/walk (8:00 a.m.)

Children's fun runs (10:45 a.m.)

Mature Mile (11:15 a.m.)

Team APDA members are asked to raise a minimum of \$250 for individual participants or \$1,000 for a "family" of 4-5 participants in exchange for:

- Free race registration.
- Team t-shirt.
- Complimentary training (marathon & half-marathon participants only).

If you're interested in participating, volunteering, or sponsoring Team APDA at GO! St. Louis on April 11-12, 2015, please call us at 314-362-3299 or email Debbie Guyer (guyerd@neuro.wustl.edu) or Sarah Schmerber (sschmerber@apdaparkinson.org).

We look forward to your participation in helping APDA fight and win this battle against Parkinson disease.

Stay tuned to our website, www.stlapda.org, or our Facebook page, Facebook. com/APDAGreater StLouisChapter, for more information and updates as we near the race weekend date.



## **Lori's Lessons**

Lori Patin challenges the progression of Parkinson Disease (PD) in the most inspirational way and bets on a cure, determined to buy time until one is found.

Sunday

**April 12, 2015** 

in downtown St. Louis

Marathon (7:00 a.m.)

Half-marathon (7:00 a.m.)

Marathon relay

(7:00 a.m.)

"Over the last 15 years, Parkinson's has taught me many lessons. While I wish I hadn't had to learn them, they have brought me comfort, strength, and blessings. I humbly offer them to you because they have taught me so much about life itself and continue to help me fight against my disease. And I hope you, too, will benefit from them when life throws challenges at you."

Lori Patin

When you are under attack, you must attack back... in your personal, maybe even very quiet way. If you run away, your challenge will catch you from behind and eat you. Relentless determination is the only omnipotent force in a tough fight. You can wear down your opponent; you've just got to want to win more.

The bravest thing you can do is to believe that bravery exists and act accordingly.

The two best drugs in the world are hope and faith. Hope for the best, plan

for the worst, and have faith that there are forces at work that are with you and forever on your side.

4 Hope creates hope. If you have hope, you will keep fighting, which creates positive results, which creates more hope – a positively reinforcing cycle. The opposite is also true; if you lose hope, you stop trying, which creates losing results – a negatively reinforcing cycle.

5 Attitude is everything. Don't just spend the rest of your life feeling sorry for yourself, sitting in a corner waiting

for the worst to happen. Instead, keep in mind that this is the one life you have and decide to make the best of it. Within the parameters of your particular challenge, the only thing you can control is yourself. Life has no real guarantees. Live with the perspective that says, "I'll give it all I've got and hope for the best."

6 Make constant "deposits" into your energy bank accounts with hugs, sunrises, and laughs. They will allow for

continued on next page

#### Lori's Lessons

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big withdrawals when you get hit with the unexpected.

Be grateful for every gift. I say a prayer each time I look at the flowers that grow from the seeds I planted.

Own and accept your situation. Don't deny full ownership or lie to others about it. Being honest with yourself about your challenge allows you to confront it rather than to hide, which just wastes time, energy, and resources. Being honest with your friends draws not scorn or isolation but sympathy, prayers, resources, and ideas to support your fight. You will be amazed at the forces that come your way if you just share your story.

Seek out communities that will nurture you. Communities are an extension and reflection of the family and they enhance life. Belong to a community, and it will celebrate with your joy and commiserate with your pain. You need the members of the community for support, and they need you as a good example. Expect to be responsible to and for the community, just as it is responsible to and for you. Isolation is a killer, and inclusion is a savior.

Set goals – realistic, achievable, but challenging goals. Goals will move you forward because they create tension between where you are and where you want to go. But you may have to redefine success. Before you got blindsided by your challenge, you measured success in certain ways. Now your situation may make you measure success differently. Before I had PD, I was an aerobics instructor. Now I am proud to be able to go ballroom dancing.

1 Decide what is really important in your life - whether it's being with family and friends, or gardening, or writing your memoirs - and make sure you spend time doing it.

1 2 Give some things up. You will be surprised what you will gain. I gave up some of my independence, and it has brought me so much closer to my family and friends.

Miracles are surely sometimes given from on high, but don't count on that kind of miracle. The most likely miracles are the ones you will create yourself with hard work and a good attitude.

#### **Lessons for Caregiving**

1 4 If you can afford to pay for help, get it. Don't be afraid to experiment, but don't do anything really dumb or risky. If you can't afford to pay, ask friends and family. People are willing, even anxious, to help. Conquer your embarrassment because the little mistake is to ask and be turned down, but the big mistake is to never ask and miss getting help.

15 Accepting help is not a sign of weakness but of strength. It takes strength to accept your limitations and to allow someone to assist you. To ask for and receive help requires the powerful combination of humility and courage.

16 Communicate. Don't expect anyone to guess what you want and need, or don't want and dislike. Mean what you say and say what you mean.

17 It is in everyone's selfish best interest to demand that our caregivers take care of themselves. It is a good idea for you also to take care of them to the best of your abilities. They can and will wear out if both they and you are not careful.

18 Your caregivers will come to realize that when the person they love and care for has a difficult challenge, so do they. Of course, the degree of ownership involved is different. Even though the challenge is primarily yours, it will confront your caregivers and affect them, too. They can even make it work for both of you if they think about it the right way.

19 Make sure your caregiver has something else in his or her life to give him or her fulfillment. A steady diet of you/you/you will get a bit stale. He or she will return refreshed after doing whatever it is that interests him or her.

The biggest challenge for your caregiver is to hate the disease, really loathe it, but not resent the person who has it. He or she may know intellectually that it is not your fault, but

every caregiver has moments of thinking, Why me? What did I do to deserve this? They have to set that aside and move on, for themselves as much as for you. Still, to underestimate the challenge of dealing with their emotions would not only be naïve but potentially destructive.

21 You must love the people who love you. Their love and care demand reciprocity. You can't just expect or demand or even accept their love and care without convincing them that you love them back. If nothing else, just tell them!

Reprinted with permission from Lori's Lessons: What Parkinson's Teaches About Life and Love by Carol Ferring Shepley.

## Q: What can I do to have less "off" time?

**A:** You need to be able to explain to your doctor when you have "off" time. Very importantly, once you begin having "off" time, you must be devout about taking your PD medication at exactly the same times each day. For instance, NOT just taking your medication "three times a day" but at specific times that are the same each day. Or NOT just taking your medication "before meals and at bedtime" unless you always eat and go to bed at exactly the same times every day. Then the second step is to be able to describe when you have "off" time with respect to when you take your medication. The most common thing is to start getting "off" time near the end of a dose OR just as you take the next dose OR even after you take the next dose (but before it has a chance to start working). You need to be able to describe which doses this happens near and how long it happens. An additional issue to consider is that you have to be able to describe what usually happens, not just when it might happen once in a while. Then with your doctor, you can begin to make changes in the amount of the medications you already take OR shorten the interval between medications OR add another medicine.

## **Best Kept Secrets – Programs And Services**

Thank you for your participation in our programs and services. We will be conducting a needs assessment and hope you will let us know what you find most and least valuable in terms of the programs and services offered through the Greater St. Louis Chapter. Here are some of the choices you will have in the coming year.

#### Caregiving

For Caregivers Only Support Group – 2nd Monday of each month, 10:30 a.m.-12:00 noon, held at the APDA Resource Center, 1415 Elbridge Payne, Ste. 150, Chesterfield, MO 63017. No need to RSVP, just come. This group is led by a professional counselor, Dr. Dee Jay Hubbard, and trained leaders Jay Bender and Lynda Wiens. All care partners and caregivers are welcome, as well as adult children of parents with Parkinson's.

Caregiver Series – back by popular demand! Registration required. Led by graduate Occupational Therapy students from Washington University School of Medicine.

- HOME-CARE and SELF-CARE (Cleaning, Cooking, and Grooming) Offered on Thursday, March 19, OR Saturday, March 21, from 10:00 a.m.-12:00 noon.
- HOME SAFETY (Durable Medical Equipment and Its Management, Safe Transfers and Fall Prevention) Offered on Thursday, March 26, OR Saturday, March 28, from 10:00 a.m.-12:00 noon.

#### **Exercise**

All exercise classes are offered weekly and are modified for people with Parkinson's and can accommodate all levels of ability. Patients are encouraged to attend at least one class per week for free, and can attend unlimited classes for a suggested donation of \$20/month. Chair exercises and Tai Chi do not require a reservation. Aquatic Classes and Tremble Clefs require a sign-up. See the calendar pages of the newsletter and/or our website for listing of all classes.

- Tai Chi is offered on Wednesdays (10:00 a.m.-11:00 a.m.) and Fridays (11:30 a.m.-12:30 p.m.)
- Aquatic Exercise is offered twice a week, year-round. Please check the calendar section of the newsletter for precise schedule and location.

#### **Support Groups**

Support groups are held in various locations throughout Missouri and southern Illinois. They are listed in the calendar pages of the newsletter and on our website, www.stlapda.org. They offer time to connect with others facing similar challenges and also offer occasional speakers or learning opportunities. Support groups are open to individuals with Parkinson disease and their family members, with the exception of our Caregiver Only Support Group. No need to RSVP – just choose a convenient location and try one out. They each have their own personalities. You are welcome to attend more than one monthly support group. If you would like to be added to the regular mailing list for a particular group, please send us an email with your request.

#### **PD101**

PD101 is an informational session for newly diagnosed individuals offered one-on-one with you and your family member(s). Debbie Guyer, Executive Director, will go through a slide presentation about Parkinson disease, answer questions, and offer additional literature and referrals to specialists. To schedule a private session, contact Debbie directly at guyerd@neuro.wustl.edu or 314-362-3299.

#### **Newsletters**

The Greater St. Louis Chapter of the APDA publishes a quarterly newsletter in February, May, August, and November of each year. Newsletters include calendars of our programs and services, articles by professionals in the field, tribute acknowledgements, and more. You must request to be added to the mailing list, and we will gladly send one to your physicians and family members, too. All LiNK newsletters since 2007 are archived on the home page of our website, and these and other newsletters are kept on file in the resource center.

#### **Tremble Clefs**

This is a nationwide program for people with Parkinson's, their family members, and care partners. The goal of this group is to be a participant-led, musical experience. Through vocal exercises, singing as a group, and playing instruments, members will come together weekly and bond over a shared joy of making music. Please call to join this wonderful group, led by music therapist, Linda McNair, which meets on Saturday afternoons from 1:30 p.m.-3:00 p.m. at Salem Methodist Church.

#### **PEP**

Parkinson Education Programs are offered three times a year. These special presentations are open to everyone in our Parkinson community as well as the general public. Announcements and invitations are mailed to your home/business if you are signed up to receive newsletters, approximately four weeks in advance of the program, and can be found on our website as well.

#### **Wallet Medication Card**

Special wallet cards containing PD medication information are available. One side contains medications not to be used by PD patients and the other side, medications to be used with caution.

All of our services and special events can be found on our website at www.stlapda.org. Our Parkinson Resource Center in Chesterfield maintains a full resource library. Stop by Monday through Friday from 7:30 a.m.-4:00 p.m. to visit and learn. As always, please contact us if you have any other questions or needs (314-362-3299).

### **Tributes & Donations** 10/1/14 – 12/31/14

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 anniversary of Courtney & Chuck Adams Roselynn Gad

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The Wedding of Elisa

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A Lifetime of Contributions to Shaare Emeth-Ronnie & Allen Brockman Gail & Larry Glenn

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Speedy recovery –
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Happy Holidays & Best Wishes -Larry & Gail Glenn Curt & Judy Fritz

The birthday of Tricia Goldman Gail Glenn

Ralph & Helen Goldsticker Larry & Andi Goldsticker

The birthday of Ralph P.
Goldsticker, Jr
Larry & Andi Goldsticker

Robert Goodson
Judy Goodson

Merry Christmas – Jane Goeringer Martha Dyer

**Debbie Guyer with thanks**Kay Bruchhauser
Rochelle Weiss

Debbie Guyer for helping Parkinsonians and their Care partners Dick & Phyllis Duesenberg

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The Hayes Family

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The 50th Anniversary of Mr. & Mrs. Gene Klein Pam & Jerry Brown

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Merry Christmas – Joe Morgan Bob Morgan

Jim Niehoff for your
tremendous attitude and
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And Patrick, Nick & Laura

The anniversary of Ron & Marilyn Oster Mary Ann & Steve Morovitz Ron & Donna Tierney

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continued on page 10

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continued from previous page

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### **Fall Prevention**

Rebecca Blum, MSOT/S 2015

alls are a significant health concern for older adults, and the rate of falls is often higher for those living with Parkinson disease (PD). NPF reports that 38% of people with Parkinson's fall each year. Falls often occur because of the symptoms and complications of PD, leading to recurrent falls.

Falls can happen both in the home and the community with negative consequences including injury, developing a fear of falling, and reduced daily functioning and independence. Parkinson disease comes with a unique set of symptoms and complications that cause people with PD to be more susceptible to falls. Some examples include joint stiffness, instability and poor balance, and "freezing" episodes during walking.

For those living with PD, it is important to understand that falls are preventable and you should not stop doing the things

you care about due to fear of falling. Below are some strategies and small lifestyle changes that can impact fall risk factors and reduce the chances of having a fall.

#### **In-Home Safety Tips**

Ensure that there is adequate lighting in every room, stairs, and pathways to make it easier and safer getting around your home. Be mindful of clutter on the floor,

continued on page 12

# Occupational Therapy – Impacting, Empowering, and Improving the Lives of Individuals with Parkinson Disease

Jamie Archer MOT, OTR/L



Washington University Occupational Therapy offers in-home services that are personalized to help you analyze and solve problems related to performing everyday

Jamie Archer

activities that can be complicated by Parkinson Disease (PD). The goal of our program is to ensure that you are able to live independently and safely at home and to maintain quality of life.

#### What is occupational therapy?

Occupational therapists work to break down barriers that limit your ability to do the things you want and need to do every day. We do this by adapting tasks and the environment to help you perform activities more independently. Occupational therapy also provides education in self-management with chronic conditions like PD to address the skills needed to manage your condition on a daily basis.

## Why is occupational therapy recommended for individuals with PD?

The neurologic changes that occur with PD can result in slowed movement, stiff joints, impaired coordination,

forgetfulness and trouble concentrating, fatigue or lack of energy, impaired balance, tripping, and falls. All of these symptoms can lead to difficulties with accomplishing everyday tasks.



## In-Home Occupational Therapy at Washington University:

With in-home therapy at Washington University, an occupational therapist comes to your home and provides a skilled evaluation to determine the areas in which you are experiencing difficulty. We do this through interviewing you and your family and/or caregivers. We also assess the physical setup of your home and the resources you have available to you. We

might also ask to observe you doing some of your normal daily activities or parts of activities to further assess your abilities. Then, we work with you to make a plan for how to address each of your personal

goals. Occupational therapists also make recommendations regarding what we think might be helpful for you to manage living with PD as you age. Once you and your therapist identify problems, you'll work together as a team to come up with solutions that may include use of adaptive equipment, making changes to your home environment, changing the way you do things, or developing new skills. After the evaluation, the occupational therapist will work with you to determine when it is best to return and begin working on each of your goals. For each

visit, we will come to your home. The number of visits is determined by your needs and your insurance coverage.

Occupational therapy services are now also available at the Movement Disorders Clinic at Washington University School of Medicine. Ask your physician if you are interested in a referral for occupational therapy.

continued on next page



# CAREGIVER SERIES SPRING 2015

A series of individual courses designed to train the caregiver for people with Parkinson disease on role-reversal skills.

Classes will be taught by OT graduate students from Washington University and other professionals & specialists in fields related to the course topics.

# SPONSORED BY Greater St. Louis Chapter APDA 1415 Elbridge Payne Rd. Ste. 150 Chesterfield, MO 63017 314-362-3299 \* www.stlapda.org





for upcoming courses! 314-362-3299

#### **COURSE #1 - Home-care & Self-care**

Cleaning, Cooking & Grooming

Offered Thursday, March 19 from 10:00 a.m. to 12:00 p.m.

OR Saturday, March 21 from 10:00 a.m. to 12:00 p.m.

#### **COURSE #2 - Home Safety**

Durable Medical Equipment & its management, transfers & falls
Offered Thursday, March 26 from 10:00 a.m. to 12:00 p.m.
OR Saturday, March 28 from 10:00 a.m. to 12:00 p.m.

All courses to be held at the APDA Resource Center 1415 Elbridge Payne Rd. Ste. 150, Chesterfield, MO 63017

APDA-Greater St. Louis Chapter February 2015 LiNK

#### **Occupational Therapy**

continued from previous page

## Who can benefit from occupational therapy?

Anyone who is experiencing difficulty with performing his or her daily activities can benefit from occupational therapy. Occupational therapists can assist individuals with PD at any stage – it's never too early. In fact, we encourage therapy services early in your diagnosis to help you maintain an active lifestyle while adjusting to changes in function caused by PD. Having an occupational therapy assessment several times throughout the course of the disease is not uncommon. Due to the progression of PD and related changes in function over time, therapists

often reassess individuals to assist with adaptations to daily activity. Caregivers of individuals with PD can also benefit from working with an occupational therapist to determine the safest ways to assist your loved one with the activities they do every day and to ensure caregiver health and well-being.

## Who covers the cost of occupational therapy?

Most health insurance plans, including Medicare Part B, cover a majority of the cost for occupational therapy services. If you have secondary insurance, it will usually cover the rest. Call the number provided below for specific details on coverage related to your insurance plan.

## How do I become eligible for these services? How do I set up an appointment?

If you think you or your loved one might benefit from in-home occupational therapy, talk to your physician and ask for a referral. Upon receipt of your referral, someone from the occupational therapy program will call you to set up an appointment at a time that is convenient for you. If you or your physician would like to learn more about Washington University's In-Home Occupational Therapy Services, contact Curtis Comer at 314-286-1669 or comerc@wusm. wustl.edu.

#### **Fall Prevention**

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such as electrical cords and loose throw rugs, which may be a cause of tripping. Keep the pathways in your home clear, especially the path from your bed to the bathroom. In the kitchen, place commonly used items on shelves that are easy to reach.

To protect against falls in the bathroom, place grab bars, a tub rail, and non-slip mats to aid in safely getting in and out of the shower or bathtub. Consider adding a raised toilet seat and/or a toilet frame to make it easier getting up and down from the toilet.

Use the Home Safety Self Assessment Tool (HSSAT) as a resource to help identify other fall risk factors in your home (http://agingresearch.buffalo.edu/hssat/), or contact an Occupational Therapist for an in-home safety assessment (see article in this newsletter for information).

#### **Exercise**

Exercise is also a highly effective way to reduce the risk of falling. Exercise helps prevent weakness or stiffness and increases endurance to participate in daily activities. There are many different types of exercises; the key is finding the right ones for you and making them a part of your daily life.

Tai Chi is one of the most effective exercises to reduce fall risks. It is an exercise that pairs slow movements and breathing and is very slow and gentle. It has been proven effective in improving balance.

There are other types of exercises that can help improve endurance, strength, and balance. These include chair exercises, walking, and water aerobics. Try to do some of these exercises with family and friends to make it more fun and engaging.

Contact the Greater St. Louis Chapter of the APDA to find an exercise class that is right for you. Other local agencies such as OASIS, Area Agency on Aging, the YMCA or the Jewish Federation may also have exercise classes.

#### **Foot Care**

Our feet are our base of support and we depend on them to help keep us balanced and safe when walking or standing. See your doctor if you have any numbness, tingling, or pain. These symptoms can negatively impact the way you walk, which can lead to a fall.

Wear footwear that is supportive and comfortable because they will keep you balanced. Types of shoes to avoid include flip-flops, slip-on shoes, shoes with heels, and shoes that don't fit adequately. Invest in a pair of slip on shoe ice grippers (available at many sporting goods stores)

to wear if you must go outside in icy weather.

#### Medication

For people with Parkinson's, medication management can be complex and difficult. Certain types of medications can contribute to the risk of having a fall including pain medication, antidepression or anxiety medication, and sleeping aids. It is important to have a good understanding about what medications you are taking, why you are taking them, and what the possible side effects are. Keep an up to date medication list of all prescription and over the counter medication and have your doctor or pharmacist review it to make sure that you are taking the appropriate medication.

## Communicate with your health care provider

In the event that a fall has occurred, it is critical to report this to a health professional. After having one fall, the chances of having another fall A health significantly increase. professional can help prevent another fall from occurring in the future. If you are experiencing frequent falls, you may want to consider keeping a fall diary. Reducing the occurrence of falls is imperative for people living with PD. Taking preventative steps to prevent falls is important for maintaining a good quality of life. Know your risks and work to minimize them during daily activities.

LINK February 2015



## **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	573-356-6036 573-434-4569
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 David Urich	573-632-5440 573-796-2395
Joplin	Jasper	Byers United Methodist Church 1730 S. Byers, Gymnasium	Every Monday	3:00 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 & 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	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	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

continued on next page



## 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 March-December	6:00 PM	Karen Ladd	217-377-4973
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	Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217-483-4300

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### **Exercise Classes**

The APDA now offers 13 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	636-733-0180 x7719
Chesterfield	St. Louis	Parkinson Resource Center 1415 Elbridge Payne, Ste. 150	Monday	1:30 PM	Becky Miller, DPT	314-362-3299
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
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Winter Session Jan. 5-March 13 Spring Session April 6-June 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	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	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	Tuesday	11:00 AM	Holly Evans, COTA	636-916-9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Winter Session Jan. 5-March 13 Spring Session April 6-June 12	1:45 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 February 2015 LiNK



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 vou in advance for helping us spend our resources wisely!

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

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## Save The Dates

#### **April 11-12, 2015**

GO! St. Louis Walk/Run Family Fitness Weekend (registration required – www.stlapda.org)

#### **April 19, 2015**

PEP Program with Dr. Mohammed Hassan from University of Connecticut (watch for invitation in the mail)

#### May 18, 2015

APDA Golf Tournament Honoring the Memory of Jack Buck (registration required)

# WINNER!

he annual APDA Golf Classic in honor of Jack Buck will take place May 18, 2015, at Algonquin Golf Club in Glendale, MO. Mark your calendars! Invitations will be mailed out soon, so don't delay in returning your registration as this event has completely sold out for the past CT BUCK MEMOR two years. We hope you'll join us in honoring a man whose own dauntless brand of charity has made him a civic institution in our community.

St. Louis Cardinals GM, John "Mo" Mozeliak, will serve as Honorary Chairperson for the sixth consecutive year. Mo's Parkinson connection is

twofold as both his grandmother and father-in-law were diagnosed with Parkinson disease. We are thrilled that Mo remains passionate about

his involvement with our cause. One of the highlights of the evening was the Q-and-A session with John Mozeliak and broadcaster Dan McLaughlin. Last year, over

PRATILISON GOLF \$115,000 was raised to support local patient services

fund Parkinson and programs and to research. Participants commented that they enjoyed the sit-down dinner and feasting on Chef Brian Bernstein's delicious creations. If you don't golf, there is a dinner-only option, but tickets are limited, so sign up early.

> If you or someone you know would like to receive an invitation to play in this wonderful tournament, become a corporate or individual sponsor, and/or donate a gift to the auction or raffle, we welcome your involvement. Please contact the Greater St. Louis APDA Chapter at 314-362-3299 or send an email to guyerd@neuro.wustl.edu.

Help us honor Jack's memory with another winner! The funds generated will assist those living with Parkinson disease in our local communities as well as the researchers hard at work discovering causes and

ultimately a cure for Parkinson disease.