

MISSION

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

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NEWSLETTER DISCLAIMER

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

ILLUMINATING DARKNESS

Deborah Guyer, MA
Executive Director



Walking to the parking garage after work recently, I passed a poster titled “Illuminating Darkness,” advertising artwork created by individuals suffering from illness. I kept thinking about the phrase, “Illuminating Darkness,” as I walked to my car and how the APDA has the unique ability to illuminate the darkness for many people by creating a connection, a link to our organization. The diagnosis of Parkinson's disease is never received with open arms. In fact, I think the symbolism of a dark cloud hovering overhead very much captures how many people feel when they hear the words, “You have Parkinson's disease.” Many people know very little about PD when they are given their diagnosis, and feel lost as to how to proceed.

Learning about PD, ways to effectively delay its progression, and coping skills, are ways to illuminate the darkness. Booklets and resources in our library abound for the readers in our community. Traditional exercise classes are offered at a growing number of locations as well as aquatic, dance, and speech exercise classes. Monthly support groups are held throughout the state. Wellness Courses focus on developing skills and confidence in managing the everyday activities and relationships that may be challenging. Our speakers series (PEP meetings) meet quarterly with over 440 patients, care partners, and professionals in attendance at our most recent event featuring

Dr. Larry Elmer, David Zid, and Jackie Russell.

I recently participated in a series of lectures provided by the American Fundraising Professionals (AFP), and they confirmed what I have been told before—the #1 reason people don't give is that they are not asked. So I am asking you to partner in our effort to illuminate the darkness for someone who may just be starting that journey. If you've gained something by participating in a program provided by the St. Louis Chapter of the APDA, consider making a contribution. If you benefit by reading these quarterly newsletters or attending our educational lectures, make a donation. I recently spoke to a caller who apologetically said that she could only make a \$25 memorial contribution for a recently deceased friend, and I lost no time in telling the donor that we accept single-dollar-bill donations and checks for \$1,000 with equal enthusiasm and appreciation. We hope that you will continue to enjoy all the services and programs provided at no cost and that you value our ability to continue to illuminate the darkness for individuals and families coping with this devastating disease. ■

UPCOMING APDA EVENTS

- Sun., June 13 Social Dance**
2:00 pm-4:00 pm at Congregation Shaare Emeth
RSVP required
Sponsored by Jack Strosnider
- Sat., June 26 Trash or Treasure?**
1:30 pm-5:30 pm at Congregation Shaare Emeth
RSVPs required with advance ticket purchase
Sponsored by Kodner Gallery
- Late August Parkinson Education Program (PEP)**
Time and location to be announced
Topic to include cognitive deficits and dementias in PD including discussion of Lewy body dementia
- Mon., Oct. 11 Fashion Show & Luncheon**
Sheraton Westport Chalet
- Sun., Nov. 21 Parkinson Education Program (PEP)**
2:00 pm-4:00 pm at Congregation Shaare Emeth
Dr. Joel Perlmutter—Update on PD Research

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or by appointment

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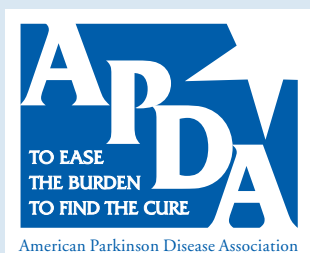
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EDITOR

Deborah D. Guyer



QUESTIONS FOR THE DOCTOR

Lee W. Tempel, MD

I experience cramping of my foot about 30 minutes before my medication is due and bad curling of my toes. It is extremely uncomfortable. Can anything be done to relieve that?

You are likely experiencing a dystonic cramping of the foot or toes because of “wearing off” of your PD medications’ effect. The most common time for this to occur, logically enough, is in the early morning after going all night without medication. It can also happen, as you describe, a certain amount of time before the next dose. The solution is the same as for other symptoms of “wearing off.” There are many different ways to approach this depending on the patient’s stage of PD, the medications already being taken, the amount of medication being taken at each dose, the interval between medication doses, etc.

There are a number of other associated issues that limit choices as well (such as having significant “peak dose” dyskinesias after doses, a history of having had delusions or hallucinations, having thought or memory difficulty, etc.). All of this information needs to be taken into account by you and your neurologist to come up with the unique solution that prevents this “wearing off” symptom. It is important to let the neurologist know before which dose or doses this occurs and by how much time. Remember “wearing off” can happen right *at* the time of the next dose or even just *after* the next dose (it takes some amount of time for that next dose to start “kicking in”). I often find it helpful as one of the early steps to be sure that all of the dose intervals are looked at carefully. For instance, if you just take medicine “four times per day” and some intervals are significantly longer than others, mak-

ing the intervals even may be one of the first things to correct.

Why is sleep so important?

Sleep is a time for the body to rejuvenate. Unfortunately, our way of life often puts a lot of time demands on us. As a result, many people in the U.S. are chronically sleep deprived. PD patients are no exception. Furthermore, patients with PD may have many other reasons to not get a good night’s sleep. They are more prone to depression,

daytime excessive drowsiness associated with PD which can throw off the day-night cycle of rest, Restless Legs Syndrome (RLS) and REM behavior sleep disorder. Sleep can be interrupted by becoming too parkinsonian overnight (especially excessively stiff). PD-associated dementia can interrupt sleep in various ways. Also, there is more likelihood of frequent trips to the bathroom at night, various aches and pains of arthritis, and a host of other causes.

Many patients tell me that on days after a good night’s sleep, their PD symptoms are clearly less. It is worth some effort to achieve good rest overnight. This includes rules to enhance the chances to get to sleep (“good sleep hygiene”) like not sleeping excessively through the day, getting at least some minimal physical activity during the day, taking at least an hour before going to bed to slow down and relax, keeping the bedroom a quiet, cool, dark place (no TV or eating), gentle stretching before going to bed, no (or very little) caffeine at night, avoiding excessive alcohol, etc.

Working with your primary physician, neurologist or sleep specialist can often minimize the causes listed above and other potential causes. ■



FACING PARKINSON'S DISEASE TOGETHER: KEYS TO SHARING THE CARE

Terri Hosto, MSW, LCSW

The terms “caregiver” and “care partner” are used to refer to a person who provides assistance to someone who needs help, such as a loved one with Parkinson’s disease (PD). Caregiving consists of a wide spectrum of duties, including driving to doctor appointments, preparing meals, assisting with aspects of personal hygiene, etc. The majority of such care is provided by family members. Family caregivers may be considered primary or secondary caregivers. A primary caregiver typically assists with multiple aspects of day-to-day care and also may act as a spokesperson for the individual being cared for. Secondary caregivers generally help with specific tasks, like grocery shopping or handling finances.

Early in the disease, the person with Parkinson’s (PwP) may remain fairly independent in all aspects of self-care, as well as in household and community activities. As symptoms increase and worsen over time, the PwP will eventually require more and more help from others. It is important that family caregivers and the PwP work together to determine when, how much, and what type of help is needed.

First, be willing to talk openly with each other about the disease and how each of you feels about it. This should occur not only at the time of diagnosis, but throughout the course of the disease, as symptoms change and problems develop. Discuss medical decisions you might face in the future, along with options for future care. The PwP should appoint a trusted individual to serve as health care proxy so that your wishes

are followed. As you learn about PD, it can be helpful to meet other people who are facing a similar situation and connect with knowledgeable community resources. Participate in support groups, attend educational programs,



and consult with health care professionals such as physical and/or occupational therapists who can help objectively assess what assistance is needed. Discuss preferences in everyday care and try to simplify everyday routines to make caregiving easier.

Secondly, give support to one another. Both sides need to be willing to make adjustments and accept help. For example, if you are the PwP, agree to have someone else stay with you while your caregiver goes out even though you think you’re fine left alone. This may help to ease your caregiver’s worry. And you, too, may benefit from socializing with someone else. By doing something that will provide your caregiver relief, you are showing support for your caregiver and giving back in return for the care given to you. Also, never underestimate the power of a sincere expression of gratitude offered to your caregiver. Caregiving is often a thankless job done out of a sense of caring and wanting

to do the right thing for a loved one. When your caregiver helps you with their best intentions, show gratitude by saying thank you.

If you are a family caregiver, it is equally important that you learn to ask for help. Don’t try to do everything yourself. Teach others to provide back-up care as needed. If someone says, “Let me know if you need anything,” be prepared to respond with a specific task in mind (e.g., “I need someone to stay with the PwP so I can go out.”). If others do not offer help, don’t let that stop you from seeking assistance. It’s likely that others don’t know what you need or how to

help. It is particularly important to arrange time off from caregiving, even for brief periods, in order to restore yourself physically and emotionally. Taking respite is one of the hardest things for family caregivers, although it is often available through various agencies such as the APDA.

Lastly, being partners in care means keeping a balance in your relationship. Each person, whether a caregiver or a care receiver, needs an individual sense of place or position in the family. It is especially important that the PwP has opportunities to feel valued by others regardless of his/her need for help. Try to focus on what the PwP can do. Celebrate successes and good days. Family caregivers must balance caregiving priorities with time for rest, relaxation and social activities outside of caregiving. It’s been said that “the care you give yourself is the care you give to your loved one.” Working together, you can be true partners in care. ■

RESPIRE CARE

Greg Trusty, Always There Homecare

For many, the challenges of caring for a loved one are part of daily life. Caregiving is a demanding, difficult job and no one is equipped to do it alone. Getting help is essential for your health, and your resilience is critical for your loved one. Respite care provides short term breaks that relieve stress, restore energy, and promote balance in your life. Working with family members or friends may be difficult, but there are many respite care options and strategies.

Respite care basics

Seeking support and maintaining one's own health are key to managing the caregiving years. Using respite care before you become exhausted, isolated, or overwhelmed is ideal, but just anticipating regular relief can be a lifesaver. Respite can take many forms, but boils down to two basic ideas: sharing the responsibility for caregiving and getting support for you. Finding the right balance requires persistence, patience, and preparation.

Planning your relief

Planning starts with analyzing needs...both yours and your loved one. As a caregiver, is support what you need most? Some free time? Help with transportation? Keep track of your daily activities; then make a list of the areas and times when you most need help. Identifying your loved one's needs, abilities, and preferences will also help you find the right match. Are social activities primary? Assistance with walking, eating or medications? Mental stimulation? Exercise? Answering these questions will help you determine which respite options to pursue.

Engaging family members in respite care

Family members and friends may be able to help out while you run an errand, take a break or even go on vaca-

tion. However, just as the burden of caregiving is often more than one person can handle, it can also be a tough process for families to share. Even the healthiest families can be severely stressed by ongoing care, and the division of labor is frequently lopsided. The following tips can encourage support and participation:

- Talk openly and regularly. Keep everyone up to date on your loved one's needs and condition. Family members who don't share the day-to-day caretaking experience may not fully appreciate the situation.
- Encourage family members to evaluate what they can reasonably and honestly do. Changing roles and varying resource levels can impact family involvement. Welcome different viewpoints, accept limitations, and be willing to try alternate strategies. Share your list of needs and take advantage of all offers to help.
- Recognize your own feelings and discuss disproportionate tasks. Harboring resentment when you need more help can lead to your burnout and impaired health. Ask directly for concrete support and specific time commitments. Consider establishing an online calendar to organize relief and reconfirm schedules.
- Use technology to bridge distances. Try free video conferencing services to hold family meetings at times that work for everyone. Create a web-based community to share updates and explore options. Sites like carepages.com keep family and friends online and in touch.
- Participate in support groups. Learning how other families cope can suggest new options and provide reassurance. When siblings are unable or unwilling to share the load, peer support can be invaluable.

In-home respite care

In-home services can be provided by a trained caregiver, occasionally or on a regular basis. Services may last from a few hours to overnight, and may be arranged directly or through an agency. This popular respite choice enables individuals to remain in their own environments, and can be invaluable for caregivers. Services may include:

- Cognitive stimulation, recreation, and companionship can be provided by home-care businesses providing trained staff to cover short in-home intervals.
- Personal care providers assist with daily living skills such as bathing, dressing, feeding, or toileting.
- Homemaker services support meal preparation, shopping, and house-keeping.

Selecting respite care services and providers

When you devote so much love and energy to caregiving, it may be difficult to entrust your family member to strangers. Whether you engage a provider directly or work through an agency, you can allay your fears by conducting some basic research. Always include the potential care recipient in the screening process if he or she is able to participate, to ensure that both parties are comfortable and that your loved one's needs are respected.

Working with agencies

Although independent providers are generally the least expensive, home care agencies and referral services are often easier to use. Use your planning lists to help these professionals better serve you.

An agency finds and places providers, handles payroll, and usually provides substitutes for sick or absent personnel. If problems occur, you also have specific

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DELAY THE DISEASE – FUNCTIONAL FITNESS

David Zid

Moving About in Crowds

Do you avoid crowds? Would you feel comfortable walking into a large sporting event or a concert? Moving about in large groups of people seems to be a problem for many people with Parkinson's. The trick is to maintain your focus on walking while keeping your balance in case the person in front of you stops suddenly, or you get pushed or bumped. These exercises will help you to multitask while walking, which is necessary to confidently move about in a crowd. (You will need a playground ball or light medicine ball for some of these exercises.) Keep working at this; good luck. Remember to always think about BIG steps. ■

WALKING WHILE BOUNCING A BALL

Bounce a ball up and down while standing in one place. When you become comfortable with this, begin to bounce the ball while walking. Bounce the ball once with each step. Try to walk slowly with big steps; stay in control. Try to work up to 20 steps and 20 bounces without missing.

PARTNER BALL BOUNCE

Face your partner and stand about 10 feet apart. Raise the ball over your head, and throw the ball to the ground using a bounce pass to your partner. Allow only one bounce before your partner catches it and bounces it back to you. Repeat 20 times. Want something more challenging? Try walking forward as your partner walks backward and bounce the ball to each other. Repeat 20 times. For a real challenge, walk backward as your partner walks forward, still bouncing the ball to each other. Repeat 20 times.

PARTNER PUSH

Stand with your partner behind you. Have your partner gently push your shoulder with enough force to cause a slight forward loss of balance. Step forward with one leg to maintain your balance, and then return to starting position. Your partner will then gently push you to the right, and then to the left. Take a step either way to maintain your balance. Lastly, your partner will tug your shoulder backward; you will take a step back and return to starting position. Make certain this is performed in a safe environment, and that your partner does not allow you to fall. Your partner will then randomly push you in all four directions; each time you will step to maintain your balance and return to starting position. Perform this exercise for three minutes – *seems like a long time but really works for balance improvement.*

WALKING WITH AN EXERCISE BAND

Stand 3 feet apart from a partner (side by side), positioned as if you are going for a walk together. Hold one end of an exercise band (or rope or long towel) with one hand while your partner holds the other end. The band or rope should have tension. As you walk, have your partner pull and release the band as you continue to walk with big steps. Try to achieve 20 steps without losing your balance.

ROTATIONAL STEP WITH A THROW

Stand with feet parallel, knees slightly bent while holding a ball. Have your partner stand to your right and slightly behind you. Take a wide step backward and to the right, turning your foot out. As you step, pass the ball to your partner with or without a bounce. Have your partner pass the ball back to you before you return to starting position. Then return to starting position while holding the ball. Repeat 10 times. Repeat this motion on the opposite side, 10 repetitions.

ROTATIONAL STEP WHILE BALANCING AN ARMLOAD

Repeat the rotational step while holding an armload of empty containers; i.e., water bottles or milk cartons. Try to carry one more than is comfortable to hold in your arms. Avoid dropping any of the containers. Alternate sides for 10 repetitions.

RESEARCH OPPORTUNITIES

Joel S. Perlmutter, MD, Director of the Movement Disorders Center at Washington University School of Medicine

At the Movement Disorders Center (MDC) at Washington University School of Medicine (WUSM), we have several research studies for which we are currently enrolling patients with Parkinson's Disease (PD) as well as healthy individuals (controls) without PD. Research is the primary way for us to learn more about PD, to develop better treatments, and most importantly, to get closer to a cure. Furthermore, studies show that people who participate in research tend to do better overall than patients who do not. So, while we hope that altruism and a desire to help the PD cause are the primary reasons people participate in research, there may actually be personal benefits as well. I wanted to take this opportunity to discuss various research projects here at the MDC for which we are currently seeking participants.

My colleagues and I have several imaging studies that need volunteers. One study is seeking to figure out why people with PD are more likely to get thinking and memory problems than people without PD. Currently, the only way to tell what sort of memory and thinking problems people with PD develop is to look at their brains under a microscope (which means you are deceased). It would be beneficial if we could try to figure out what sorts of memory and thinking changes people get while they are still alive and we are trying to figure that out with this study. For this research, we need people with PD over the age of 50, both with and without memory and thinking impairment. In addition, we need healthy subjects without PD over the age of 50 (without a first degree family member with PD) for a "control" group (this means you spouses!). To do this study, you would do either a 30-minute interview about memory and thinking or a 1.5 hour assessment of thinking and memory (depending on what PD patients can tolerate). You would

also have an hour-long MRI (a tube-like machine that takes pictures of your brain, both structure and function of your brain) and an hour-long PET scan (a machine that takes pictures of the way your brain functions). You must return yearly or every other year for an annual assessment of your memory and for additional MRIs. You must also agree to donate your brain to the Movement Disorders group here at WUSM at the time of your death. Most religions agree with brain donation and your family is given the brain autopsy results. If you are interested, please call Johanna Hartlein at 314-362-0420 or email johanna@npg.wustl.edu.

We have another imaging study for people with PD who have undergone bilateral (both sides) deep brain stimulation for PD. We are trying to figure out exactly how these stimulators work in peoples' brains so that we can figure out which parts of the brain may be activated and deactivated by stimulators, as well as which stimulation points may affect motor symptoms (like tremor, slowness, rigidity, etc.) and which points may affect thinking and memory. For this study, we need people who have stimulators for PD and who could tolerate being off their medicine for two separate 8-hour study days. Subjects also cannot have major thinking problems and must have a motor response to stimulation. For one of the study days, we complete a CT scan (takes pictures of where the stimulators are in your brain) followed by a PET scan (takes pictures of the way your brain is working). We look at your brain with different stimulator settings and different contacts. The following day, we do lots of movement tasks like measurements of your rigidity and gait, as well as thinking and memory games, which are again completed with different stimulator settings and contacts. If you are



interested, please call Johanna Hartlein at 314-362-0420 or email johanna@npg.wustl.edu.

We are currently enrolling volunteers for several **treatment** studies. Currently, there are no procedures or medicines that are "neuroprotective" for PD. That means that while we can give medications to treat the symptoms of PD, there is nothing that

will slow the progression of the disease. For that reason, researchers around the world are looking for medicines or supplements that may slow or stop the progression of PD. One such study by the Parkinson Study Group (PSG) being done here at the MDC is seeking people who have PD who are not yet taking any medicine for PD (such as Sinemet, Mirapex, Requip, or Azilect). That means this study is looking to catch people early on in their disease who haven't yet started PD meds (or if you have taken them for less than 90 days total, you must be willing to stop them). This is a 16-month study where people either get 1200 mg or 2400 mg of Coenzyme Q10 (a nutritional supplement) or get a placebo (sugar pill). For this study, people cannot have any significant thinking or memory problems or any current serious cardiac problems. People also must believe that they could go at least 3 or 4 months without starting medicine for PD symptoms. This study is being done at many sites in the US, Canada, and Puerto Rico, and enrollment ends this summer. If you are interested, please call Johanna Hartlein at 314-362-0420 or email johanna@npg.wustl.edu.

Another study for neuroprotection supported by the Parkinson Study Group and being done here at WUSM is trying to uncover whether a medicine called Isradipine (Dynacirc CR) may slow or halt the progression of PD. As in the Coenzyme Q10 study,

RESEARCH OPPORTUNITIES

continued from previous page

we are looking for patients with PD early in the course of their disease (diagnosed for 3 years or less) who have never taken medicine for their PD symptoms. Isradipine CR is approved by the FDA and marketed in the United States for the treatment of high blood pressure, but this study will also help indicate if it is safe, well tolerated, and if it will slow the progression of PD. If interested, please contact Mary at 314-747-7017.

Another ongoing treatment study looking for volunteers is being led by Paul Kotzbauer and Brad Racette, two doctors at the MDC. The study is using carbidopa/levodopa in the form of an intestinal gel that is infused into the small intestine via a tube and controlled by a small pump worn by the patient in a fanny pack or holster. Many people with PD respond well to carbidopa/levodopa tablets (Sinemet) but eventu-

ally develop difficulty with fluctuations between the “on” and “off” states, as well as dyskinesias or involuntary movements. These fluctuations in symptoms are primarily related to fluctuations in medication levels that occur after each dose with carbidopa/levodopa tablets. This new intestinal gel infusion system delivers the medication at a constant rate directly where it is absorbed in the small intestine, and bypasses the unpredictable time required for tablets to move from the stomach to small intestine. It may allow people to remain more consistently in the “on” state without experiencing wearing off or troublesome dyskinesias. To qualify for the study, patients must have idiopathic PD and be experiencing difficulty with fluctuations in their symptoms while taking carbidopa/levodopa tablets, with at least 3 hours of off time per day during waking hours despite efforts to optimize their medications. There is an online tool for this study to see if you may be eligible, located at www.advancedPD-

study.com. You may also call Pat Depen, if interested, at 314-362-8548.

For all of the above studies, you must have Idiopathic PD to be included. If you have other serious neurologic problems such as history of stroke, seizures, major loss of consciousness (like from a car accident or near drowning), or if you are in poor health because of a serious condition such as current cancer or advanced heart disease, you would likely not be eligible for these studies. No costs will be incurred by you or your insurance, and some studies actually compensate for your time and inconvenience. Remember that it is because of research that we know as much as we do today about PD and without people willing to do research, we could never “Ease the Burden or Find the Cure.” We appreciate your potential interest in our studies and would welcome the opportunity to give you more information about various research studies being conducted at our Center. ■

RESPITE CARE

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avenues of recourse (complaints, mediation, or arbitration) that are not available when working with individuals.

Referral services work to match your needs with local program options. Use online registries, check newspaper ads or the yellow pages to find specialists who know local programs and can help you navigate their systems.

Paying for respite care

In today’s challenging economy, you may think respite services are unattainable. However, thinking creatively can uncover valuable resources:

- Traditional funding sources for respite care
- Personal Assets/Insurance: Although medical insurance generally does not include respite coverage unless licensed medical professionals are involved, long term care

policies usually fund services up to specific time or dollar limits.

- Veterans’ Benefits: The VA provides inpatient respite coverage for up to 30 days per year for qualified veterans. In addition, when wartime vets care for their spouses, funding for in-home services are available on a state-by-state basis.

Strategies for successful respite care

Finding and implementing respite care sounds like a lot of work. Relief and revitalization is not important for you alone; it benefits all touched by the caregiving process.

- Evaluate often. Observe your care recipient before and after respite sessions. Ask for brief updates and more detailed reports regularly.
- Expect changes. Respite care is a process that often requires fine-tuning. Anticipating and accepting changes in personnel or programs

can keep you from becoming discouraged.

- Attend your support group regularly. Structured and informal groups allow you to meet others in situations much like yours. You can talk, vent, laugh, and exchange tips with people who understand. If you can’t easily leave home, online communities, message boards and forums can provide much-needed support. ■

MOVING?

Don’t forget to change your address with the APDA. Returned mailings waste valuable resources (money) needed for research, patient services and operational expenses. Please notify us of ANY changes by email to byersc@neuro.wustl.edu or mailing an address correction to **APDA, Campus Box 8111, 660 S. Euclid Ave., St. Louis, MO 63110.**



MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted. Support Group day and time may change periodically. For current updates on support groups and exercise classes, call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Cape Girardeau	Cape Girardeau	The Chateau Girardeau 3120 Independence St.	Feb. 1, Aug. 2	3:30 PM	Desma Reno, RN, MSN	573-651-2939
		St. Francis Med. Ctr. 211 St. Francis Dr. SFMC Cafeteria	May 3, Nov. 1	6:00 PM		
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Doris Heuer Mary Green	573-815-3718
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Julie Berthold Paula Simmons	314-355-6100
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Monday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	St. Johns Regional Medical Ctr. 2931 McClelland	Mondays	1:30 PM	Nancy Dunaway	417-659-6694
Kirkwood	St. Louis	Kirkwood United Methodist 201 W. Adams	1st Monday	7:00 PM	Terri Hosto, MSW, LCSW	314-286-2418
Kirkwood/Oakland	St. Louis	Bethesda Dillworth 9645 Big Bend	3rd Friday	10:00 AM	Laurel Willis, BSW Shellie Eswine, BSW	314-373-7036 314-446-2186
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy Dalton	573-964-6534
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
Sedalia	Pettis	First Christian Church (Disciples of Christ) 200 South Limit	3rd Monday	4:00 PM	Barbara Schulz	660-826-6039
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
St. Peters	St. Charles	1st Baptist Church of Harvester 4075 Hwy. 94 S.	1st Tuesday	1:00 PM	Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Riverview at the Park 21997 White Sands Rd. Solarium	2nd Wednesday	10:00 AM	Jean Grifford	573-543-2162
West County	St. Louis	Congregation Shaare Emeth 11645 Ladue Rd. Library	1st Wednesday	2:30 PM	Lisa Ackerman	314-725-1888
St. Louis	St. Louis	Pre/Post-DBS Temple Israel 10675 Ladue Rd.	3rd Thursday	1:00 PM	Steve Balven Stan Wilensky	314-249-8812 314-997-5114
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	Jeff Wilsey Rich Hofmann	314-614-4560 314-369-2624



ILLINOIS SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted. Support Group day and time may change periodically. For current updates on support groups and exercise classes, call the APDA Information & Referral Center or the facilitator, Information that has changed since the last **LiNK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Mary Friedrich Jodi Gardner	618-234-4410 x7031 or 7033
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Tom Hippensteel	618-684-4282
Carmi	White	Phoenix Rehab. & Nursing 615 West Webb St.	4th Tuesday	1:00 PM	Carolyn Chastain	618-387-1970
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 PM	Cathy Watts	217-428-7716
Granite City	Madison	St. Johns United Church of Christ 2901 Nameoki	1st Thursday	1:30 PM Call to verify	Hilda Few Karen Trim	618-797-0527 618-345-3222
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Matoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Marcia Smith	217-254-4869
Mt. Vernon	Jefferson	Greentree of Mt. Vernon, 2nd Floor	4th Thursday	6:30 PM	Donna & Bill Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr.	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Dan Vonberg	217-546-2125
Vandalia	Fayette	Fayette County Hospital 650 West Taylor, Conference Room	Last Tuesday	1:00 PM	Charlene "Pokie" Pryor	618-283-4633

SOME KIND OF WONDERFUL

Something wonderful happened on Saturday, April 17. Over 440 patients, caregivers and healthcare professionals gathered for the Parkinson Education Program (PEP) "Hope & Empowerment" sponsored by Teva Neuroscience. Dr. Larry Elmer, Chief of the Movement Disorder Division and Director of the Parkinson's Disease and Movement Disorders Program at the Toledo College of Medicine, was featured. He was informative, entertaining and hopeful about the future for Parkinson's patients as he addressed non-motor aspects of PD, in addition

to emerging pharmacologic treatments for Parkinson's disease.

David Zid, a professional fitness instructor and author of the book and corresponding DVD, *Delay the Disease*, and Jackie Russell, a nurse who has collaborated with David to develop a Parkinson's specific exercise plan rounded out the seminar bringing the audience to their feet and on the edge of their chairs performing simple exercises to enhance their functional skills. The crowd was treated to a day of learning that left them encouraged and inspired to go home and begin to exercise with

the hope of slowing down the progression of their disease.

Also, the audience was asked to reflect on the value of the day and consider placing just \$5 into the tribute envelopes on their tables. Over \$2,200 was collected from those in attendance in appreciation for such a fine educational experience. This provides seed money to feature another guest speaker in August, when we will address cognitive deficits and Lewy body dementia.

To purchase a DVD of this event for \$15, contact the APDA Information and Referral Center at 314-362-3299. ■



EXERCISE CLASSES

Our Exercise Classes meet once a week or otherwise as noted.
Information that has changed since the last **LiNK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	Barnes Extended Care 401 Corporate Park Dr.	Wednesday & Friday	1:30 PM	Sue Tucker, OT Mike Scheller, OT	314-289-4325
Chesterfield	St. Louis	St. John's Mercy Rehabilitation Hospital 14561 N. Outer 40	Tuesday	1:00 PM	Deb Luetkemeyer, PT	314-881-4200
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	10:30 AM	Patty Seeling, PT	314-205-6934
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Sue Tucker, OT Mike Scheller, OT	314-289-4325
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Ste. 117	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, PT	636-916-9650
North St. Louis County	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Shannon Crouch, PTA	314-355-6100
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534
St. Louis City	St. Louis	The Rehab. Institute of St. Louis 4455 Duncan Ave.	Thursday	Noon	Janelle Davis, PT	314-658-3858

NEW EXERCISE CLASS

A new exercise class for individuals with PD is being offered at The Rehabilitation Institute of St. Louis (TRISL) starting on May 20, every Thursday, 12:00-1:00 p.m., led by Janelle Davis, PT. Call the APDA Information & Referral Center (314-362-3299) to register for this weekly exercise class.

Classes will be held in the third floor gym at 4455 Duncan Avenue, in the **city** of St. Louis and free parking is available across the street in a paved lot and accessible parking on the side of the building. Duncan Ave. is easily reached from Forest Park Ave., east of Kingshighway and west of Grand.

The APDA is indebted to TRISL for their willingness to provide an exercise class for PwP living in the city of St. Louis and Illinois communities near to downtown. ■

SUPPORT DOGS

Bill Dahlkamp
Support Dogs, Inc.

Support Dogs, Inc. is a St. Louis-based nonprofit organization that places assistance dogs with people with special needs – whether they are physical, hearing, or emotional needs. The dogs help the individual lead a more productive life while providing companionship along with their service skills.

Support Dogs places dogs with individuals with PD to assist with mobility-related tasks and day-to-day functions, such as retrieving dropped items. The dog is taught to retrieve any size item – something as small as the back of an earring or contact lens and give it back to the individual. The dogs can also walk alongside the person and act as a balance mechanism so that the individual does not fall. The dogs have also been known to “break” the individual out of a freeze, providing the momentum for the individual to begin, or continue, moving. Since the dogs are certified to exceed Assistance Dogs International



standards, these dogs are certified to accompany their master in all public places of accommodation.

When someone applies for a service dog, Support Dogs gathers information and makes decisions on a case-by-case basis. The Support Dogs’ staff is incredibly dedicated to providing the best trained dog for the person, based on the person’s need and situation. All of the dogs are placed at no cost to the individual, although they cost approximately \$15,000 to raise and train.

If anyone is interested in obtaining a dog through Support Dogs, Inc., they simply need to contact the office at 314-997-2325 or by email at info@supportdogs.org. ■

TRIBUTES & DONATIONS

Tributes are a wonderful way to acknowledge the memory of a beloved person as well as honor those who mean so much to you. Tribute envelopes can be obtained from the Center 314-362-3299 or made directly on the St. Louis APDA website, www.stlapda.org, by clicking on the **Donate** link (on the right side of the home page).

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HULL OF A RACE

In 2006, an idea for a fundraiser to benefit Parkinson's disease research was born in Hannibal, Missouri, by Lori Griffith, a physical therapist and runner. Lori was the founder of the Mark Twain Area Parkinson's Support Group. The group was small, but it supported Lori as plans were set in motion in early 2006 for a 5K run. The run

would be held in the Hull, IL, area, a farming community across the Mississippi River from Hannibal, MO. Held in conjunction with the annual Hull Picnic, the 5K race, named Hull of a Race, was run through the fields of corn and soybeans and the quiet streets of the Hull community on a sunny Saturday in August. With the help of community

volunteers, Lori and the support group raised \$2,300 for Parkinson research.

Four years later with the same small number of support group members and a larger group of volunteers, the race was bigger than ever before, almost doubling in the number of competitors. The money raised in 2009 alone equaled the amount donated

in the first three years combined. Much of this growth is attributed to the 1999 graduating class of West Pike High School in Kinderhook, IL, who took it upon themselves to add a community project to their ten-year reunion celebration. This unique group of young people plans to continue their support and even-

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VETERANS WITH PARKINSON'S... THERE MAY BE REAL HELP AVAILABLE FOR YOU

Stephen C. Jones

Are you a veteran or loved one of a veteran who is battling Parkinson's disease and the mounting medical costs associated with the disease? No doubt many of you have already reached out to the Veterans Administration only to be told that there was no assistance available. At long last this appears to be changing with several big developments occurring over the course of the last two years for veterans with PD.

When most people think of the assistance available for our veterans, their thoughts turn to the Compensation Program. This program pays a benefit to veterans who were injured during the performance of their duty. Essentially, disability compensation is a non-taxable, monthly benefit paid to veterans who are disabled as a result of an injury or illness that was incurred or aggravated during their military service. The amount of the compensation is based upon the level of disability the Veterans Administration determines to be present. Those determinations are made in terms of a percentage of disability. The greater the percentage of disability the greater the level of compensation received by the veteran. You might think of this program as being similar to the workers compensation program for veterans. For a veteran determined to be 30% disabled and has a spouse, the family would receive \$421 per month in compensation. For a veteran determined to be 100% disabled and has a spouse, the family would receive \$2,823 per month. The amounts received are in addition to any other income, pension or retirement benefits being received by the veteran. Unlike some other assistance programs, there is no means

test related to the disability compensation program.

Traditionally, the problem for veterans with PD has been linking their illness to their service. They must prove that their PD was related to or aggravated by their service to our country. With many older individuals suffering from PD as part of the normal aging process, proving such a connection was difficult, if not impossible. This all changed on October 13, 2009, when Secretary of Veterans Affairs Eric K. Shinseki announced that PD, along with two other illnesses, was being recognized as a "presumed" illness for those who served in Vietnam. Studies relied upon by the Veterans Administration demonstrated a link between the herbicides they used in Vietnam called Agent Orange and PD. This represents a huge change. Now those same veterans with PD need only demonstrate they served in Vietnam during the war and their PD is presumed to be related to their service. The determination shifts to what percentage of disability is present.

In a more recent development, Shinseki on March 9, 2010, announced a new plan to "fast track the veterans' claims process for service-connected presumptive illnesses due to Agent Orange exposure during the Vietnam War." This new effort is designed to improve the processing time for the 200,000 claims the Veterans Administration anticipates receiving over the course of the next two years as a result of the three new presumptive illnesses, including PD.

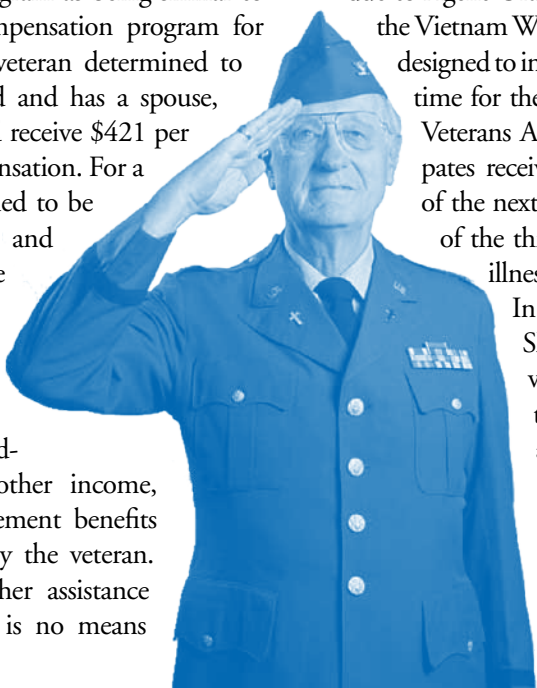
In his press release, Shinseki encourages veterans to submit their claims as soon as possible to begin the important compensation process.

Merely looking at the press release might lead

veterans to the conclusion that the presumption will only apply to veterans who served during Vietnam in country. While that is certainly the easiest way to receive benefits, the Veterans Administration is recognizing that others not formally stationed in that country were exposed to Agent Orange. The Agent Orange was assembled and handled by military personnel in the United States and throughout the world. Additionally, there is a listing of naval ships that operated in and around Vietnam that would have been exposed to Agent Orange. While slightly more work is involved, disability compensation claims for these veterans can be obtained as well. For more information related to the disability compensation, you may want to visit www.va.gov. For additional information about Agent Orange and related exposures, you can visit www.publichealth.va.gov/exposures/agentorange.

So, what about veterans suffering from PD who did not serve during Vietnam? There may still be assistance for you as well. There is another benefit called the Service Pension benefit that is available to personnel who served ninety consecutive days and one of those days was during a time of war. There is no requirement that your service during time of war actually be in the war zone. For the Service Pension there are three levels of benefits with the highest level being referred to as Aid and Attendance. For married veterans, the maximum benefit they can receive under the Aid and Attendance program is \$1,949 per month. Unlike the Disability Compensation benefit, the Service Pension is a means-tested benefit, so your income and your assets do affect how much benefit you might be eligible to receive.

Stephen C. Jones is the Founder and Managing Member of Stephen Jones & Associates, LLC, a firm that focuses on Elder Law, Long Term Care Planning, Veteran's Benefits and Special Needs Planning. ■



SERVICES OFFERED BY THE ST. LOUIS CHAPTER

Respite Care

Respite care affords a full-time care provider “time-out” to relax and/or take care of their own personal needs.

- *In Home*
(4 hours/week=16 hours/month)
Services provided include personal care, light housekeeping, help at mealtimes, and stimulating activities.
- *Adult Day Care*
(8 hours/week=32 hours/month).

Respite care is a Shared Cost Patient Service, with monthly fees based on income (sliding scale) plus an annual \$25 participation fee.

Emergency Monitoring Systems

Emergency response systems ensure that a person living alone can get quick assistance whenever needed, 24 hours/day, 365 days/year.

Emergency monitoring systems are available for those who demonstrate a financial need at a cost of \$25/year.

Adaptive Equipment

Small adaptive equipment is available at no charge for those in need. Items include plate guards, pill cutters, pill boxes and timers, built-up utensils, button hooks, long-handled shoe horns, zipper pulls, magnifiers, and more.

Medical Equipment/Loan Closet

New or gently used durable medical equipment available for loan: motorized scooters, power and manual wheelchairs, rollators, walkers, electric hospital beds, hoist lifts, bedrails, canes, lifts, ramps, pedal exercisers, and more.

This medical equipment is made available for those people with Parkinson's disease who do not have a means to pay for equipment needed in order to remain independent and in their own homes. Individuals with PD who cannot afford insurance co-pays, have insurance which does not cover the specific equipment needed, or no insurance at all qualify for loans from this equipment closet.

Website

Visit www.stlapda.org to view and download previous newsletters and educational material, learn about services and upcoming programs, make donations through Pay Pal, link to clinical trials and ongoing research, order materials and educational program DVDs or exercise videos.

Satellite Resource Center

The satellite resource center is an educational venue available for computer use to connect to a Parkinson website or view a webinar, print articles from the internet, browse through books and booklets on caregiving, exercise, incontinence, sleep disturbances, medication, and more, watch a DVD or VHS on topics related to Parkinson's disease, and visit with an interested and dedicated volunteer.

1415 Elbridge Payne, Suite 168
Chesterfield, MO 63017
636-537-5455

Open Monday–Wednesday
11:00 a.m.–3:00 p.m.
and by appointment

Literature

The following free booklets, educational supplements and pamphlets are available to view and download at www.stlapda.org or by contacting the St. Louis APDA.

- *Be Active – Exercise Booklet*
- *Aquatic Exercise*
- *Be Independent*
- *Young Parkinson's Disease Handbook*
- *Good Nutrition*
- *My Mommy has PD*
- *Speaking Effectively – Speech & Swallowing*
- *Introduction to Parkinson's Disease*
- *Parkinson Disease Handbook*
- *Keys to Caregiving*
- *Hospitalization of a Parkinson Patient*
- *Parkinson's Disease and Oral Health*

- *The Living Will & Durable Power of Attorney for Health Care*
- *The Family Unit & Parkinson's Disease*
- *The Challenge of Parkinson's Disease: Adapting to a Nursing Home*
- *Medical Management of Parkinson's Disease, includes Medications Approved for Treatment of PD in the USA – November 2008*
- *When Should PD Patients Go to the Emergency Room?*
- *Neuro-Ophthalmology & PD*
- *Fatigue in Parkinson's Disease*
- *Dr. Andrew Weil's Recommendation for Healthy Aging*
- *Depression and Parkinson's Disease*
- *Incontinence and Parkinson's Disease*
- *Employment & Parkinson's Disease*
- *Constipation & Parkinson's Disease*
- *Basic Information about Parkinson's Disease*
- *How to Start a Support Group*
- *Importance of Having a Will*
- *Medications to be Avoided or Used with Caution in Parkinson's Disease*
- *34 Helpful Hints*

For more information on any of the services described in this article please contact the St. Louis APDA Information & Referral Center, 314-362-3299, or visit www.stlapda.org. ■

HULL OF A RACE

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tually take over the race committee in an effort to expand the race and increase donations toward research for Parkinson's disease.

Fun, good exercise, and community togetherness – all working side by side toward a common goal. The 5th annual Hull of a Race will be held Saturday, August 21, 2010. Contact Marilyn White at 217-432-5262 for further information, and join them in the efforts to raise even more funds for Parkinson's research this year. ■

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

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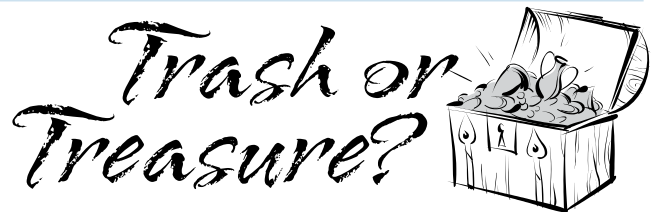
The St. Louis Chapter of the American Parkinson Disease Association
presents:



Sunday, June 13, 2010
2:00 – 4:00pm
Congregation Shaare Emeth
11645 Ladue Road
(corner of Ladue & Ballas)

Recent research suggests that those with PD may be able to dance their way to better health. Come to socialize and enjoy an open dance floor with a live DJ. Gammon Earhart, PhD, PT also will discuss the benefits of dance for people with PD. Visit www.stlapda.org for more information.

FREE
Must RSVP by 6/7/10
314-362-3299 or byersc@neuro.wustl.edu
Sponsored by Jack Strosnider



Saturday, June 26, 2010
1:30 – 5:30pm
Congregation Shaare Emeth
11645 Ladue Road
(corner of Ladue & Ballas)

Raid your attic for items you think might be worth something! In cooperation with Kodner Gallery, professional appraisers will be on hand to tell you if your item is really Trash or Treasure. Visit www.stlapda.org for additional details. (firearms, knives, swords or other weapons will not be allowed)

\$35 for admission and 1 appraisal item
\$10 for each additional appraisal item (limit of 3)
Must RSVP with payment by 6/14/10
314-362-3299

All proceeds benefit the St. Louis APDA