

February 2013: Vol. 27, Issue 1

### Mission

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

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### NEWSLETTER 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."

# St.Louis APDA

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

# THAT'S A WINNER!

e are proud to announce the establishment of the Jack Buck Memorial Parkinson Golf Classic. The first annual Classic will take place May 20, 2013, at a new venue, Algonquin Golf Club. Mark your calendars accordingly, and please join us in honoring a man whose own dauntless brand of charity has made him a civic institution.

Joe Buck, who also has been recognized for his charity work in the St. Louis community, embraces the idea of putting his father's name towards Parkinson fundraising. Joe is "happy and

mother was diagnosed late in life, but it was still a struggle in her final years. My father-in-law was vibrant, brilliant, and loved life. As the disease took over his body, his mind stayed strong, but he no longer could handle simple tasks that we all take for granted. ... As hard as it is to watch someone you love suffer, it is just as hard to see the toll it takes on the spouse and family."

You, your neighbors, your children and/or other family or friends may wish to—



honored" and sees the golf tournament as more than a chance to honor "a great man who had an inextinguishable joy for life."

St. Louis Cardinals GM John "Mo" Mozeliak will serve as Honorary Chairperson for the fourth consecutive year. Mo's Parkinson connection, as he explained it on-air last year to broadcaster Dan McLaughlin, is "twofold. My grandmother and my father-in-law were both diagnosed with this horrible disease. My grand-

- receive an invitation to play in this tournament
- become a corporate or individual sponsor
- donate a gift to the auction

and we would welcome your involvement. Please contact the APDA Center at 314-362-3299 or send an email to brooksmi@neuro.wustl.edu or to guyerd@neuro.wustl.edu.

Help us honor Jack with a winner! The funds you generate will assist those living with Parkinson disease in our local community as well as the researchers at the Advanced Center for Parkinson Research.

### APDA GREATER ST. LOUIS CHAPTER

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# LESSONS LEARNED IN THE BUSH ABOUT PARKINSON DISEASE

Brad Racette, MD, Professor and Vice Chairman of Neurology, Washington University School of Medicine

or the past five years, we have been conducting a novel research project in South Africa on the effects of manganese on the parts of the brain affected in PD. South Africa contains 85% of the world's manganese reserves and is one of the leading exporters of manganese in the world. Manganese from South Africa is used in steel throughout the world. To conduct this study we took advantage of a South African law entitling families of deceased miners to a heart and lung autopsy performed free of charge. Families are compensated if certain lung diseases are diagnosed by the pathologist. Our study takes advantage of this law by asking families of deceased manganese miners to donate the brains of the deceased manganese miner for research. The goal of this project was to determine whether chronic occupational exposure to manganese is associated with damage to the same parts of the brain as PD and if manganese miners had early PD pathologic changes. Studying environmental toxins in people exposed at work is a common way to determine the role of a toxin in PD, since it is much easier to determine a person's level of exposure at work as compared to home exposures.

The South African manganese miner study has the potential to teach us which parts of the brain are damaged by chronic manganese exposure and may definitively link manganese to PD risk. A study like this is not possible in the US, where the life expectancies are long and most workers live decades beyond when they finish working. Moreover, there is no systematic program to obtain autopsies from deceased workers in the US. Since we began to collect brains from deceased miners approximately four years ago, we have obtained brains from nearly 60 miners and are just beginning to analyze the specimens in a

subset of manganese miners and compare these to non-manganese miners. Once the brains are shipped to Washington University from our colleagues in South Africa, we perform MRI scans of the brains, a project led by Dr. Susan Criswell. Using special MRI techniques, Dr. Criswell has demonstrated in a publication in the journal Neurotoxicology that manganese deposits are throughout the brain in these workers and that manganese remains in the brain for years after exposure, contrary to previous research. This means that once manganese enters the brain, it can continue to damage sensitive structures for years. Our initial autopsy results demonstrate that astrocyte and neuron counts are lower in the same parts of the brain that we find PET abnormalities in manganese exposed welders. This is important because astrocytes are support cells in the brain that keep neurons healthy and functioning. Therefore, our study suggests that manganese toxicity may start with damage to the support cells and then neurons may start to die. This is also consistent with some theories of how neurons may die in PD and provides a potential new avenue for preventing neuron death (and disease progression) by finding ways to support the astrocytes.

While our current study does not directly study PD given the small size and focused study population, our next study will be very ambitious and will try to provide a more clear link to PD pathology by studying a much larger number of brains and by using more sensitive techniques that will require transporting brain tissue to the US very quickly after a miner dies. Thanks to APDA support, we have also begun a project to investigate the role of iron

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# LESSONS LEARNED IN THE BUSH

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in PD by studying the effects of working in iron mines on the brain. Iron has been implicated in the pathology of PD,

and this study will be the first to investigate whether workers with chronic iron exposure develop early PD pathology.

This study follows several recent studies we have published that demonstrate a potential role of manganese in the etiology of PD and as a potential disease modifier. In 2010, Dr. Susan Criswell was the lead author on a study published in the journal Neurology that described damage to the dopamine system, using PET imaging, in welders chronically exposed to manganese. Dr. Allison Willis is the lead author on several studies that investigate the risk of PD in people exposed to manganese in the community and the impact of community manganese exposure on PD survival. In a study published in the journal American Journal of Epidemiology, we described a two-fold increase risk of PD in elderly Americans living near industries that emit high concentrations of manganese into the environment, as compared to Americans living in regions with low manganese emissions. Living in a region with high industrial manganese emission may also influence dis-



Dr. Racette teaching South African medical students

ease progression in elderly Americans with PD, according to another study we published in early 2012 in the journal *Archives of Neurology*. In that study, we investigated the six-year survival of PD patients using Medicare data and found

that PD patients living in regions with high industrial manganese emissions have reduced life expectancy compared to PD patients living in regions with low manganese emissions. We concluded community exposure to manganese may modulate the progression of PD in the elderly. In other words, where one

lives after PD diagnosis may affect the rate of disease progression and types of disease complications that develop.

These studies show how data from varied study populations can be integrated to investigate various aspects of neurotoxins in humans. Ultimately, our goal of these studies is to understand causes of PD and, if the evidence is strong, reduce the number of new PD diagnoses by reducing environmental exposures.

One of the most unexpected findings from our recent work is the potential role of environmental factors on disease progression. If confirmed in future studies, reducing environmental exposures could play a critical role in slowing disease progression. Most importantly, our research shows the value of international collaborations to take advantage of unique opportunities to investigate neurotoxins.

## Paper Dolls

Debbie Guyer, MA Executive Director

hinking back to my childhood, I can't recall ever cutting out paper dolls, but the concept today intrigues me. The image of figures with outstretched arms touching and being connected to one another, fingers-tofingers, is one I'd like you to ponder, as it conveys the sense that we are all interconnected. And if we are all linked, then we should be interested in helping one another. We, in fact, are all connected. Whether by having the disease, being a family member or a care provider, being an adult child of a parent with PD, or a spouse of someone suffering from Parkinson disease, we're all in this together. Some of us are bigger stakeholders than others. But we all stand to gain if and

when the researchers here and around the world find a cure.

I am pleased to report that several of you were first-time donors since our May newsletter (perhaps as a result of reading the front page article "11.8%"). Please don't stop believing or get discouraged as time marches on. You have to know what you are treating in order to effectively know how to eradicate it. Our research is directed at finding out what causes the disease, how to measure and slow its progression, diagnose it earlier, and ultimately find the cure.



We do touch each other, and we are all connected. Consider getting involved if only to pre-empt a crisis. Encourage your adult children to learn more about the disease. They may ultimately become your care providers, and they will make better decisions knowing more about the disease progression. We now have *The Parkinson Journey* DVD, which is being distribut-

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### PAPER DOLLS

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ed not only across Missouri and Illinois, but around the country in an effort to educate physicians, healthcare professionals, nursing facilities, the public, and others who interact and deal with patients and families with Parkinson disease today. There is so much to learn!

You have many opportunities to visit the new APDA Community Resource Center, which is staffed by wonderful volunteers and staff members of the Greater St. Louis Chapter and the APDA Information & Referral Center. The Center is located in West St. Louis County and is easily accessible from Highway 40/64. We are open Monday through Friday from 7:30 AM to 4:00 PM and some evenings by appointment. The facility is dedicated to improving the quality of life for those living with and touched by Parkinson Disease.

Traveling west on I-64/40, you will pass I-270 and 141, and then exit at #20

Chesterfield Parkway. At the top of the exit ramp, turn left (crossing back over Highway 64/40). You will travel past the first stoplight (Schoettler Valley) and at the second stoplight, turn right on Elbridge Payne. We are located in the office building on the left, 1415 Elbridge Payne. Enter the main doors and pass through the lobby. You will stop in front of our door, Suite 150. See map below.

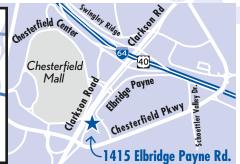
Traveling east on I-64/40 from St. Charles/O'Fallon, you will exit at Clarkson Road and turn right, heading south, past the main entrance to Chesterfield Mall. The very next exit is Chesterfield Parkway. You will exit to the right and

pass under Clarkson Road turning right onto the Parkway. Pass PF Chang's (first stoplight) and turn left on Elbridge Payne. We are located in the office building to the left behind PF Chang's parking lot. Enter the main doors and pass through the lobby on the way to Suite 150.

Best Kept Secretary
WELLNESS
COURSE meets for 6

couples, led by occupational therapists experienced with PD.





# AN APPLE A DAY...

Peter A. LeWitt, MD

Director, Parkinson Disease & Movement Disorders Clinic, Henry Ford Hospital West Bloomfield; Professor of Neurology, Wayne State University School of Medicine; President, Michigan Parkinson Foundation and Member, MPF Professional Advisory Board.

n yet another example of folk wisdom ringing true, a recent publication by Harvard Medical School researchers suggests that "an apple a day keeps the doctor away." This survey shows that the frequent consumption of apples lowers risk for developing Parkinson Disease (PD) by almost 50% (at least for the men surveyed in the study). This conclusion came from extensive investigation of lifestyle and health outcomes in almost 150,000 persons.

The observed protection against PD likely was conferred by nutritional components of fruits and berries termed flavonoids. Nutritional influences like flavonoids are just the latest addition to several recognized environmental factors influencing the risk for PD. Searching for the cause or causes of Parkinson

disease has become a highpaced research endeavor in recent years. As an example of worldwide scientific productivity, the dietary flavonoid study joins hundreds of scholarly articles published on this topic in this year alone.

Almost two centuries ago, James Parkinson, a British general practitioner, described what he termed the "shaking palsy." Today, the medical grasp on PD has progressed beyond mere description of its symptoms to abundant clues as to its origins. Nerve cells selectively lost in the Parkinsonian brain possess several vulnerabilities that might explain their gradual decline. The deleterious effects of oxygen, defective handling of worn-out cellular proteins, and impaired energy-generating mechanisms are just some of the promising hypotheses for causation; some of these ideas already have been tested in proof-of-concept clinical trials. Many researchers envision an interplay between genetic sposition and environmental risk rs (such as the foods we eat—or fail

predisposition and environmental risk factors (such as the foods we eat—or fail to). Some curious findings have arisen from investigations of lifestyle choices. For example, cigarette smoking, despite its otherwise dismal influence on health,

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### AN APPLE A DAY...

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greatly lowers Parkinson disease risk. So does caffeine intake. Otherwise, few clues help to explain why some people are more likely to develop this disorder, which, in some ways, caricatures the elderly but clearly differs from normal aging. In fact, many persons with Parkinson disease, like Michael J. Fox, first manifest symptoms younger than 40 years. Genetic factors may have a role in those with a younger age of onset but probably not for those developing this condition at its typical age of onset (between 55-60 years) or later.

Why hasn't modern medical research found how to avert or at least slow disease progression? One answer is that laboratory and epidemiological discoveries, like dietary effects in a population, do not readily translate into clinical treatments for PD. To test the effects

of a flavonoid-rich diet as a protective treatment, for example, would take many years and thousands of study participants. However, it would be great to have a simple answer for what to do when this disorder is mild and, even better, before it develops in the first place. To accomplish further understanding of PD, however, more research funds are needed and so, let your state and national legislators know that we need their support.

It would be a nice irony if a bowl of fruit and not costly medications held promise for disease prevention. Like those Parkinson disease patients who have found that Tai Chi, tango lessons, or even more mundane forms of exercise have brought them great benefits, the scientific community also has to be aware that the next round of advances might come from unexpected directions. Until then, the regular practice of optimism, as one of my patients told

me, is highly advisable. ■

If readers are interested in the medical article to which the title refers, it appeared in April 2012 in the journal Neurology with Alberto Ascherio as one of the authors. Dr. LeWitt's article is appearing in the Link with permission granted by the author and the Michigan Parkinson Foundation, where it first appeared in the Messenger newsletter, Summer 2012.

Kept Secrets
FOR
CAREGIVERS
ONLY ASSISTED

ONLY sessions occur monthly, giving those involved in the care of a person with PD a special time to share experiences with others. Led by a professional counselor, Dr. D.J. Hubbard, and other specially trained individuals.

# DENTAL HEALTH AND PARKINSON DISEASE

James M. Noble, MD, MS, CPH, Assistant Professor of Neurology at Harlem Hospital Center, Columbia University College of Physicians & Surgeons at The Neurological Institute at Columbia University Medical Center

f you or a loved one is living with Parkinson disease (PD), you are surely aware of its complexities. Among these, one that is often overlooked by both neurologists and people with Parkinson disease is dental health.

Why is it so important to address dental health issues? Poor dental hygiene can affect nutrition and increase risk for stroke, cognitive impairment, and weight loss. Parkinson disease often poses unique challenges in establishing and maintaining an effective dental treatment strategy. People of all ages with PD face similar challenges, but for those who are older, the problems can be especially serious.

### **Barriers to Dental Health in PD**

The factors accounting for diminished dental care in PD are both physical and behavioral.

### Physical Barriers

The physical symptoms of PD present challenges both for daily home dental hygiene and periodic office examinations. In 2000, David Kaplan, DDS, a retired Columbia University dentist, noted that in people with PD, "major components of oral hygiene and home care programs...require muscle-eye coordination, digital dexterity, and tongue-cheek-lip control. Tremor and the associated loss and/or lessening of the above faculties mitigate against effective oral hygiene procedures."

Indeed, because of poor motor function, nearly half of all people with PD have difficulty with their daily oral hygiene regimen. For example, people with PD are less likely than others in their age group to clean their dentures daily.

Parkinson symptoms—such as tremor, rigidity, and abnormal posture—may

make a dentist's examination more difficult. Weakened swallowing ability can increase the risk of aspiration (choking) from some treatments typically used by dentists. Additionally, people with PD who have been on medications like levodopa for several years may begin to develop dyskinesias, which can affect the jaw (where they are called oro-buccal dyskinesias) as well as teeth grinding — both of which may create problems during dental exams and at home.

People with PD may also experience dry mouth, which can contribute to or worsen already existing chewing difficulties or denture discomfort.

### **Behavioral Barriers**

In addition to the motor-related difficulties associated with PD, there are behavioral changes that may negatively impact dental care. These include apa-

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### DENTAL HEALTH AND PD

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thy, depression, and forgetfulness, all of which may lead a person with PD to pay less attention to his or her daily dental health. Other behavior changes can affect nutrition. For example, people with PD require greater caloric intake than those without PD, but some individuals will actually experience decreased appetite. This problem, combined with poor dental hygiene, often leads to a tendency to avoid nutrient-rich foods, like vegetables, which require the ability to chew well. It can also lead some people to develop a "sweet tooth" which may put them at greater risk for cavities.

People with PD may also experience some level of cognitive impairment, ranging from mild to severe. This sometimes leads to a decline in the practice and effectiveness of many daily self-care routines, including dental hygiene. People who experience cognitive changes may also be more likely to miss dental appointments and less likely to report dental pain to their caregivers or dentist, meaning problems may go unaddressed for too long.

There are early signs to look for if you are worried that your own dental care, or that of a loved one, is declining. These include infrequent tooth-brushing, difficulties rinsing during daily dental care, poor denture care, and trouble sitting through meals.

### Strategies for Improving Dental Care

Clearly, the sooner that attention is given to preventive dental care, the better. So what can a person with PD or a caregiver do to ensure that Parkinson disease does not stand in the way of good dental hygiene? Here are a few tips:

### Maintaining Dental Care at Home

Perhaps the simplest intervention is an electric toothbrush, which provides the fine and repetitive motions that protect teeth most effectively. In some people with Parkinson disease, "one-handed preventive strategies," which allow a person to use the stronger side of his or her body, can also be helpful.

For instance, some find that caring for dentures is made easier by attaching a nailbrush to a household surface with a suction cup and then moving the denture back and forth across the brush.

Additionally, people with PD may find prescription strength, topical stannous fluoride gel treatments a good preventive strategy, both on a daily basis at home and during periodic visits to the dentist. Stannous fluoride is often used in toothpastes to protect tooth enamel from cavities, but it is also available as

# Tips for Maintaining and Improving Dental Health

- Use an electric toothbrush.
- Try "one-handed strategies," which allow you to use the stronger side of your body.
- Apply stannous fluoride gel treatments, as directed by your dentist.
- Try non-alcohol based mouthwashes using chlorhexidine or baking soda.
- Visit your dentist in the morning.
- Take levodopa (Sinemet) 60-90 minutes before your visit.
- Plan several, shorter dentist visits, rather than fewer, longer ones.

a gel that can be directly applied to the mouth. Since this is a much stronger treatment than that found in tooth-paste, your dentist should be consulted to recommend the dosage and frequency of use.

Mouthwashes are generally discouraged for people with PD because they present the risk of choking, but in cases where they are still an option, it is best to look for those that are non-alcohol based and that use either chlorhexidine (an antiseptic) or baking soda. A good alternative is a chlorhexidine brush, which is a swab laden with chlorhexidine that you can apply to your teeth. They are available only by prescription, so you will need to consult your dentist.

### Improving Dental Visits

There are several ways in which people with PD and their caregivers can improve the value of their visits to the dentist, beginning with timing them strategically. For example, it is wise to plan for early morning visits, when waiting times tend to be shorter. Additionally, it's best to take levodopa 60-90 minutes prior to the office visit to take advantage of a peak response period, which may improve the patient's ability to meet the demands of a dental examination. Finally, it may be helpful to plan a series of several brief office visits rather than fewer longer visits. As PD progresses, the amount of time during which a person responds optimally to PD medications will become less and less, so shorter visits may be more realistic and more productive.

# Considering Medications and Surgery

As PD progresses, motor symptoms worsen and anxiety may increase, making home dental care and routine dental work more difficult. A neurologist will often be able to help in such situations, weighing the risks of medications with the potential benefit of a dental intervention. If invasive procedures, such as tooth restoration, are indicated, these should be undertaken as early as possible in the progression of PD, to minimize risk. If general anesthesia is required for a procedure, the patient should be warned that the recovery period for a person with PD may be prolonged.

### Conclusion

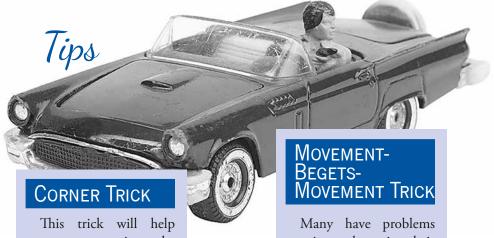
This informal list of suggestions to improve oral health is not comprehensive, but it offers a framework for intervention based on the best available (albeit limited) data. Thankfully, researchers with multidisciplinary interests are actively investigating links between neurologic and oral health. We hope that their findings will ultimately result in interventions that improve oral health in people living with Parkinson disease.

This article was originally published in 2011 as a fact sheet on the Parkinson's Disease Foundation (PDF) website. It is reprinted in its entirety, with permission from PDF. For other fact sheets, please visit www.pdf.org/factsheets.

# Delay the Disease - Getting out of a Car

David Zid, BA, ACE, APG, Certified Functional Fitness Trainer

etting out of a car is difficult for most people with Parkinson disease. The seat is low and frequently hard to slide across. Our class had an open discussion of their personal struggles with this move, and we came up with a few tricks and corresponding exercises that might make it easier for you to get out of your car. Practice all of the following. These tasks will help you maneuver in a tight space, unfreeze after a period of sitting, and increase your flexibility and ability to rotate yourself out of the car seat. Good luck.



This trick will help you maneuver into the tight space of a car, where people frequently become frozen. Walk to a corner of a room and stand for a minute. Take a big rotational step and open your stance, making sure you are not crossing your legs as you step. Now walk out of the corner. Repeat 5 times, turning both directions.

Many have problems moving and rotating their feet out of the car after sitting for a long time. A few minutes before you get to your destination, start moving any body parts. Roll your shoulders and move your feet or legs. This can help with the larger movement of getting your legs out of the car.

### WINDOW TRICK

You will need a partner to perform this. If you are seated in the front passenger seat, roll the window all the way down. Open the car door and rotate yourself so that you are facing the open door, with your feet out of the car. Your partner now will close the door partially, so that the door is barely touching your legs. With both hands, grab the bottom opening of the window. Now have your partner open the door as you continue to hold on, thus pulling you out of the seat into a standing position.

# Exercises

### SEATED SIDE STEPS

Start in a seated position on the edge of your chair with your feet flat on the floor. Using high knees, walk your feet around to the right side of the chair, rotating your head and shoulders with your legs. Using the same motion, walk your feet around to the left side of the chair. Perform 5 – 10 reps.

### SIDE-TO-SIDE TWO-LEG LIFT

In a seated position with your feet flat on the floor, and using both hands to hold on to the sides of the chair, pick up both knees and swing them to the left side of the chair. Then pick up your knees and swing to the right side of chair. Perform 5 – 10 reps.

### **BICEP CURLS**

Hold hand weights, a weighted bar, or even soup cans in each hand. Stand with your knees slightly flexed or remain seated. Keeping your elbows close in at your sides, curl weights up to chest level with your palms up. Slowly return to starting position, with control. Repeat 7 - 10 times. Now repeat the same move with your palms facing in towards your body; repeat 7 - 10 times.

# 12-INCH BOX (ADVANCED)

Find a 12- to 16-inch high box, step, or bench. A fireplace hearth works well. Stand with your back to this box and squat down as far as you can without touching it. Return to a standing position. Repeat 2-5 times.

# PT4PD

Ryan Duncan, PT, DPT, Beth Crowner, PT, DPT, NCS, MPPA, Gammon Earhart, PhD, PT Washington University School of Medicine, Program in Physical Therapy

n recent years, there has been a steady increase in the number of research studies detailing the effectiveness of exercise and physical therapy for people with Parkinson disease (PD). There are numerous benefits of exercise for people with PD, including, but not limited to, improvements in walking speed, balance, quality of life, cardiovascular fitness, and overall participation in daily activities. Different modes of exercise, such as treadmill walking, high intensity cycling, strength training, walking with cues, balance exercises, dance, and tai chi have all resulted in improved physical benefits for people with PD. As such, it is important to stick with a regular program of exercise. Physical therapists can help people with PD to develop appropriate exercise programs. Therapists with specialized training in treating people with PD are preferred because the symptoms and rate of disease progression associated with PD can be very different between two people. Therefore, individualized and patient-centered treatment by a physical therapist with in-depth knowledge of PD and medical management of PD is very important.

Physical therapists can also identify a person's risk for falling and determine who needs balance rehabilitation. People with PD fall more often than people without PD, and these falls pose devastating consequences such as hip fracture and reduced quality of life. Our recent research suggests that we can accurately predict whether or not a person with PD will fall in the subsequent six months by using standardized balance measures. The importance of this fall risk assessment should not be understated. If a person with PD is determined to be at risk for falls following this assessment, physical therapy can then be provided in an effort to improve movement and

reduce the probability of future falls.

Given that exercise and fall risk assessment are tremendously important for people with PD, we at Washington University Program in Physical Therapy

to specialized, multidisciplinary care for people with PD by developing a network of physical therapists and other healthcare professionals throughout the greater St. Louis area who are specially



People with PD fall more often than people without PD.

launched "Physical Therapy for Parkinson Disease (PT4PD)" in January 2013. Employed in this clinic are physical therapists uniquely trained to evaluate and treat people with PD, who often experience movement deficits not easily identified and treated by physical therapists without such training. The goals of this clinical service are to 1) optimize independence in all parts of life, 2) enhance mobility, 3) maintain or improve physical and functional capacity, and 4) reduce the risk of falls for people with PD. Furthermore, we can work with caregivers to help them implement safe movement strategies and support home exercise programs for their loved ones. PT4PD provides evidence-based treatments and exercise programs tailored specifically to each person's needs. In the future, we hope to enhance access

trained to care for people with PD.

To be evaluated by a physical therapist at PT4PD, you must first obtain a prescription for physical therapy (PT) from your neurologist or primary care physician. Prescriptions should be faxed to 314-286-1473. To schedule an appointment, call our office at 314-286-1940, or feel free to contact Ryan Duncan for further information: 314-286-1478 or

duncanr@wusm.wustl.edu. ■

Rept Secrets

MONDAY

CHAIR EXERCISE

CLASS at our Parkinson
Community Resource Center meets
each week from 1:00-2:00 PM. Class
is led by Susan Mayer, MHS, PT
and has openings for new
participants.



# 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**. \*Info subject to change.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	1:30 PM	Gayle Truesdell	636-923-2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	11:00 AM	Dee Jay Hubbard	314-362-3299
Chesterfield	St. Louis	Pre/Post-DBS Group APDA Community Resource Center 1415 Elbridge Payne, Suite 150	3rd Thursday	1:00 PM	Steve Balven	314-249-8812
Chesterfield	St. Louis	ACOP Support Group APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Thursday, February 21	6:15 PM	Debbie Guyer Mark Hoemann	314-362-3299 636-278-5197
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton Doris Heuer	573-964-6534 573-434-4569 573-999-2106
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	Britt-Marie Schiller, PhD Rich Hofmann	314-754-3256 314-369-2624
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Melissa McGuire Nancy Robb	314-355-6100 314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Mondays	2:00 PM	Nancy Dunaway	417-623-5560
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 ext.56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW	314-286-2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy Dalton	573-964-6534 573-434-4569
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
Springfield	Greene	Park Crest Baptist Church 816 W. Republic Road	Last Thursday	11:00 AM	Kay Meyer	417-350-1665



### continued from previous page

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
St. Peters	St. Charles	Spencer Road Library 427 Spencer Road, Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem.Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Griffard, RN	573-543-2162
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314-713-4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Wentzville	St. Charles	Twin Oaks at Heritage Pointe 228 Savannah Terrace	1st Thursday	1:00 PM	Ann Ritter, RN Sherrie Rieves	636-336-3168 636-542-5400



# **EXERCISE CLASSES**

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

O:b.	County	Masting Cita	Day of Mostins	Time	, Loodor/o\	Dhana
City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	11:00 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	Gardenview Chesterfield 1025 Chesterfield Pointe Parkway	Thursday	1:00 PM	<b>Brandon Sunderlik</b> Faye Bienstock	618-971-5477 314-917-9983
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday	10:00 AM	Craig Miller	314-362-3299
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Monday	1:00 PM	Susan Mayer, MHSPT	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Winter session Jan. 7-Mar. 15 Spring session April 8-June 14	11:30 AM Thursdays	Brenda Neumann	636-896-0999 ext. 21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Monday	2:00 PM	Nancy Dunaway	417-623-5560
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314-289-4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Healthwise Center 6 Jungermann Circle	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, COTA	636-916-9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Winter session Jan. 7-Mar. 15 Spring session April 8-June 14	2:00 PM Thursdays	Brenda Neumann	636-896-0999 ext. 21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534



# ILLINOIS SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Jodi Gardner	618-234-4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, M.D.	618-549-7507
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	Kathy Broaddus	217-820-3096
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Marilynn Kozyak Jeanette Kowalski	618-288-3508 618-288-9843
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Mattoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217-268-4428
McLeansboro	Hamilton	Heritage Woods - Fox Meadows 605 S. Marshall Ave., Dining Room	1st Wednesday	1:00 PM	Paula K. Mason	618-643-3868
Mt. Vernon	Jefferson	Greentree of Mt. Vernon 2nd Floor	4th Thursday	6:30 pm	Donna 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. www.parkinsonssupportcentralill.org	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

# DOCUMENTATION OF CHARITABLE CONTRIBUTIONS

Brian Hantsbarger, St. Louis APDA Treasurer, Conner-Ash P.C.

t is that time of the year—time to start gathering your documents together for your tax preparer. The purpose of this article is to give you some guidance as to what documentation you should have for cash contributions to a charitable organization. Non-cash donations have a different set of rules and are not considered in this article. The documentation for a cash donation depends on the amount of the donation and whether or not goods or services were received.

For a donation of any amount, if you receive goods or services, the amount you can deduct is the amount you pay

that is more than the value of the item. Let's say you bought an auction basket for \$60. If the basket is worth \$50, you can deduct \$10.

If you paid more than \$75, the organization must give you a statement which includes a good faith estimate of the value of those goods and services. An example of this would be the fee to play golf in the APDA tournament.

For every contribution of \$250 or more, the organization must give you a statement of the amount of your contribution and the value of any goods or services received (or a statement that no goods or services were received). An ex-



ample of this would be an annual cash donation of \$500 to APDA.

If the documentation you have does not meet these guidelines or is received after the due date for filing returns, the IRS can (and often times has) disallow the deduction in its entirety.

## **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.

### **HONORING**

The special birthday of Courtney Adams Roselynn Gad

The great granddaughter of Leona Altman Roberta Hayman

Bernard Armbruster Janis Cellini

Don Blackwood Christy Dolbeare Joyce King

Robert Coulter
Catherine L. Rudolph

Celeste Dillon Wilma Earline Hayes

Mary Dwyer Your Bunko Group

Jeanne & Harry Effinger
Nicole Effinger
Matthew & Tricia
Harrison

Bill Erdman Christine Hayes

Marge Evans David Elsbree

Edward C. Fogarty
Dr. & Mrs. William
Fogarty

Merry Christmas Mr. & Mrs. Steve Frank Sharon Frank

The 60th Anniversary of Elaine & Charles Fremder Sara Lee Fitter

The Gatesworth Support Group Maureen Neusel

Vernon William Gerth, III Bill & Erika Gerth

Jane Goeringer Mary Kay Venvertloh

The 91st birthday of Ralph Goldsticker Larry, Andi, Julie, Daniel, & Rachel Goldsticker Ralph Herzmark

The 80th birthday of Bob Greenberg Sid & Frances Axelbaum

The marriage of Cheryl Griffin & Steve Stone Larry & Gail Glenn

Brian Hantsbarger Conner Ash, P.C.

Merry Christmas Mr. & Mrs. George Heckel Joe & Donna Marshall

Steve Hurster Citizens National Bank Sara Lee Fitter

Gene Lane
Janice McConnell

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Landgraf
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Lauren Schroeder

Charlotte Shelburne Sharon & John Baldwin

Martin Shrader Stephen & Judith Ellenburg Judith Ugalde

*David Smith*Janie Smith

*Jack Strosnider*Parkinson Exercise Group
- Garden Villas South

The special birthdays of Bill & Terri Taylor Roselynn Gad Randee Fendelman

Support Group Presentation by Dr. Mwiza Ushe Debbie Guyer

The special birthday of Daniel Von Berg The Raymond Family

Merry Christmas Daniel &

Carola Von Berg
The Raymond Family

Patsy C. Walker Jane Walker

Merry Christmas Mr. & Mrs. Jack Wheeler Joe & Donna Marshall

Bob Wiens Debbie Jacobson

### REMEMBERING

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Alice Edelman
Debbie Guyer
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Susan Kennedy
Constance Ray
Jack Strosnider

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Sarah & Brendan Bunts
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Kristin Freeze

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Steve & Marsha Morgner
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Nelda Devine

continued on next page

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continued from previous page

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Volume 27, Issue 1 St. Louis APDA **Link** 

Nancy Grandcolas

Art & Jo Greenwood



The Optimism campaign recognizes individuals who contribute \$500 or more during each calendar year.

Parkinson families conducted successful events and we wanted to showcase their efforts to inspire you to consider small ways you can increase awareness and help generate funds to ease the burden and find a cure. Take the challenge and host your own Optimism Event.

### **OPTIMISM JAMS**

Tribute for musician Joey Marshall raised \$1500 for the St. Louis Chapter.

### **OPTIMISM BOWLS**

Rich Jacques friends and family raised \$1340 at a bowling event for PD.

# OPTIMISM 10,000 CLUB MEMBERS 2012

Hull of a Race Rodger & Paula Riney Scottrade

# OPTIMISM 15,000 CLUB MEMBERS 2012

With Open Hearts Fund

# OPTIMISM 5000 CLUB MEMBERS 2012

Jim & Anna Blair

Carol House

Community Partnership at Benton

Jeff & Lotta Fox

Nancy Rapp

Wells Fargo Commercial Banking

### OPTIMISM 3000 CLUB MEMBERS 2012

Thomas & Charlotte Benton Chuck & Carol Borchelt Delmar Gardens Enterprises Express Scripts, Inc. Hilliker Corporation Erma O'Brien Bruce Schneider Joan Slay

# OPTIMISM 2000 CLUB MEMBERS 2012 David David

David Dankmyer (& Financial
Management Partners)
Jim Guller (& Coopenative Home
Healthcare)
Steve & Lynn Hurster
Mark & Nancy Kodner
Dave Kaercher
Moneta Group

### OPTIMISM IN-KIND DONORS 2012

Autohaus
Robert Sanderson (Alphagraphics)
Barry Roufa (FastSigns of Bridgeton)
Sweet B's
David Kodner personal jeweler
Kodner Gallery
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2012

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### OPTIMISM 500 CLUB MEMBERS 2012

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continued on next page

Industries

### HELP WANTED

eeking volunteers with experience and interest in marketing and/or public relations. Volunteers will join a committee to help promote the St. Louis Chapter of the APDA and its activities. In any given week, we serve hundreds of patients and their families through our support groups, exercise classes, and educational programs. For more information, contact Debbie Guyer at guyerd@neuro.wustl.edu or 314-362-3299.

Other volunteers needed

- to serve at our Chesterfield Parkinson community resource center
- to register participants at our Parkinson Education Programs (PEP meetings)
- to help with mailings and literature orders
- to help spread the word about APDA in our communities
- to serve on a speaker's bureau
- to participate in health fairs
- to serve on a new Walk/Run committee for an annual event

CROWD will resume in the spring. The

group meets twice a month for 3 month period to practice use of appropriate loudness levels using LSVT-techniques.

### **OPTIMISM 500**

### continued from previous page

Royal Banks of Missouri Sylvia Saddler Schnadig International Corp. Doxey Sheldon David Sherman,III St. Peters Exercise Class Sunrise Senior Living Frank Thurman Vouga Elder Law, LLC Whalen Custom Homes, Inc. Wolff Properties Jean & Bob Wunderlich Don & Norma Ziegenhorn Dick & Margie Zimmerman

# DID YOU KNOW...

 More than 132,000 people will be diagnosed with Parkinson Disease in this country this year alone.

 Life expectancy improves by seeing a neurologist in addition to your internist or family practitioner if you have PD.

- Currently there are no laboratory tests to detect Parkinson Disease.
   Diagnoses are based primarily on thorough case histories and observations by a neurologist trained in movement disorders, and sometimes a response or lack of response to medication.
- These 10 often-missed early signs of PD: 1)loss of the ability to smell, 2) sleep dysfunction (acting out their dreams), 3) constipation and other elimination problems, 4) loss of facial expression, 5) persistent neck pain, 6)slow, cramped handwriting, 7) voice and speech changes, 8) lack of arm swing, 9) excessive sweating, 10) changes in mood and personality and memory (concentrating, problem solving, multitasking, and planning).
- Melanoma (skin cancer) and PD might have shared environmental or genetic risk factors or pathogenic pathways. Have yearly body checks by a dermatologist and examine your skin once a month. People with PD have an estimated two- to six-fold increased risk of melanoma but a reduced risk of most other types of cancer.
- Charlie Rose's Brain Series discusses Parkinson Disease and Huntington's Disease. There is a link to this hopeful discussion on our website.
- Max Little (TED Talks) reveals a breakthrough technique to monitor and potentially screen for PD through a simple voice recording (listen to this fascinating discussion on our website www.stlapda.org.
- PD causes an array of non-motor symptoms which may elude detection by doctors and even patients themselves. Patients and caregivers feel the burden of these non-motor symptoms. Many of these symptoms seem to affect the mind more than the body. For example, depression, anxiety, irritability, and social withdrawal are all recognized now as non-motor symptoms of PD. Experts believe they are caused not by the person's reactions to having PD but by the disease itself and how it changes the physical brain. (Dr. Black will be addressing these issues on April 13 at the PEP meeting.) Inform your neurologist (Movement Disorders specialist) about any changes in mood, attitude, and behavior (lack of energy, loss of endurance, cognitive problems).
- Recent research has found that PD begins years and possibly decades before motor problems appear.

Best Kept Secrets
SHARED
COST SERVICES are

available for those with financial needs.

This program provides assistance for in-home respite care, adult day services, in-home chore assistance, and travel reimbursement, emergency response systems for those who live alone.

Call for application.

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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Has your doctor received his/her complimentary copy of the recently released DVD, *The Parkinson Journey*? Do you want your children to learn about this chronic, progressive disease?

Don't give up your personal copy; let us send one to them.

Call with your physician's name and an address or phone number and a copy will be provided free of charge.

### SAVE THE DATE!



ACOP,
the adult children
of parents with Parkinso

of parents with Parkinson support group, will meet one evening every quarter to discuss issues faced by adult children involved in their parents care.

Tell your children about this wonderful group!

### Sat., Apr. 13 Parkinson Education Program (PEP)

Dr. Kevin J. Black, a neuropsychiatrist at Washington University School of Medicine, will give a presentation entitled "Who Are You and What Have You Done to My Spouse/Caregiver?" where he will address the roles depression, apathy, anxiety, delusions, and impulse-control disorders can play in Parkinson disease (before, during, and after the patient has been medicated). Families may feel robbed of a formerly vital and vibrant, entertaining loved one. Come learn how and why this happens and how you can cope with this "new" person in your life.

DoubleTree by Hilton Hotel & Conference Center, 16625 Swingley Ridge Road in Chesterfield (63017)

10:30 AM to noon

### **UPCOMING PD EXPERT BRIEFINGS**, 12:00 noon (CST)

Register @ www.pdf.org for online seminars

- Tue., Mar. 12 Under-recognized Non-Motor Symptoms of Parkinson Disease
  Dr. K. Ray Chaudhuri, Kings College London
- Tue., Apr. 16 Medical Therapies: What's in the Parkinson Pipeline?
  Dr. Kapil D. Sethi, Georgia Health Sciences System
- Tue., June 4 Improving Communication in Parkinson Disease: One Voice, Many Listeners

Angela Roberts-South, MA, CCC-SLP, Ph.D. Candidate, Western University, Ontario, Canada