

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.”

RACIAL AND GEOGRAPHIC VARIATION IN PD

Allison Wright Willis, MD

Dr. Willis is an Assistant Professor of Neurology at Washington University School of Medicine. Her clinical areas of expertise include treatment of adults and children with movement disorders; such as, Parkinson disease (PD), dystonia and Tourette Syndrome/meltds. Her main area of research is in the environmental epidemiology of PD.

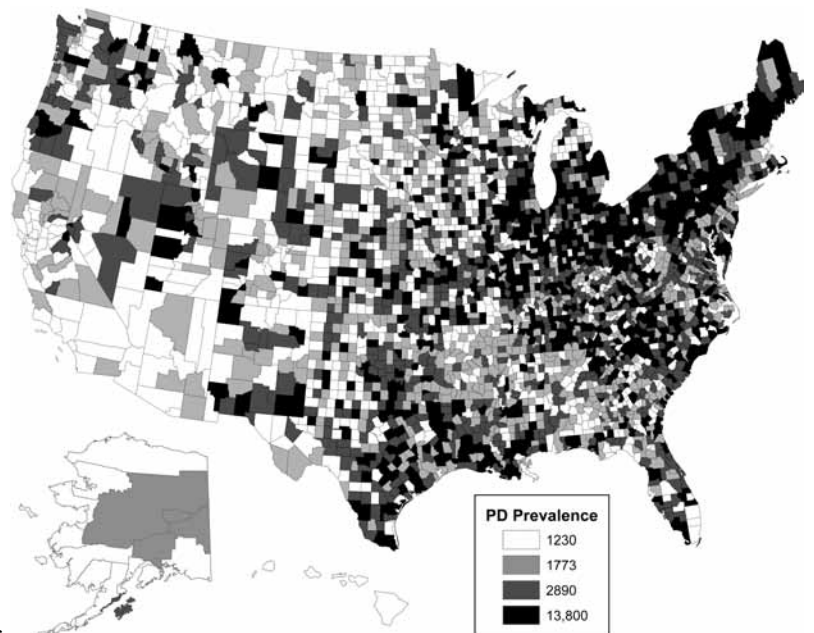


Parkinson disease is a common neurodegenerative disease of the elderly with no known cause. My research seeks to identify demographic and environmental factors which may influence who develops PD and who does not. Previously, we did not know how common PD was in the U.S., nor did we have extensive data on which people are more likely to develop the disease. Using Medicare data, which is utilized by 98% of Americans over the age of 65, we were able to determine PD rates in the U.S. by race and region of residence. Following are highlights from my recently published article in the journal *Neuroepidemiology* (Wright Willis, A., et al, *Neuroepidemiology* 2010; 34:143-151).

We found that PD affects approximately 1.6% of the U.S. population over the age of 65. Approximately 130,000 people are newly diagnosed each year. Men are slightly more likely to have the disease, with a male: female ratio of 1.55 (155 men have the disease for every 100 women). PD rates increase with age. White men have a much higher rate of PD, up to double that seen in Blacks or Asians. Asian women seem to have the lowest rate of

PD in the U.S.. Geographically, PD rates are highest in the Midwest and Northeast regions of our country, where the rates of new and existing cases of PD are two to ten times greater than that in the West and South.

There are several interesting theories suggested by this recent study. The finding that Whites have substantially higher rates of PD may mean that Blacks and Asians are somehow less susceptible to PD, perhaps due to a protective genetic factor, or to decreased exposure to key environmental factors. The finding that PD is more common in the Midwest and Northeast supports previous research which suggests that non-hereditary PD may be associated with environmental factors (some of which may be pesticides or metals). These areas of the country are hubs of agriculture and industry, and future studies may be able to identify specific environmental factors which raise or lower PD risk. ■



Age, race and sex standardized prevalence (per 100,000) of Parkinson Disease among Medicare beneficiaries in the United States (year = 2003).

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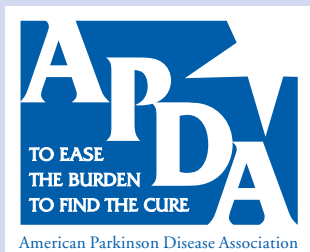
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Deborah D. Guyer



I DON'T WANT TO BURDEN MY CHILDREN

Sarah Movius Schurr, LCSW

In my work meeting with support groups, facilitating family meetings and talking on the HelpLine, a familiar theme I encounter is that many folks are worried that as they get older or their care needs increase their Parkinson's disease will make them a burden on their children. Of course, this is a natural concern and demonstrates an awareness and caring for



those around us. Yet most all of us will need to call on loved ones during tough times, as well we should. As a caregiver for an older relative, I can appreciate the strains that chronic illness places on families. Here are some tips to help make the road as smooth as possible with your family.

Ask for help before you need it.

Don't wait until your need for help is urgent and family has to drop everything to deal with a crisis. Let your kids begin to help you out while your needs are still small. Gradually add more help as it becomes appropriate. It will be easier for your family to adjust to a gradual increase in care needs than to be caught off guard by an emergency.

Spend their inheritance. Too often people don't pay for the care they need because they want to save money to leave to the next generation. For some that means risking a fall in the shower because you didn't want to pay for a bath assistant or living alone when you really need to have support available for safety reasons. Generally speaking, your family would rather worry about you less today than have your money tomorrow.

Be blunt. Ask for what you need as clearly as possible. Tell your kids exactly what the situation is when you have a problem to work out. Gently

hinting that something is wrong may lead to an incorrect assumption of what your true needs are.

Hire a Lawyer. See an elder-law attorney and get a good estate plan in place. Get a power of attorney set up so someone can do business for you if you are in the hospital or otherwise unable to care for things. Make sure your children are informed of your decisions. A good estate plan is especially

important if you have investments or multiple properties.

Get on the calendar. You may have noticed – your children have very busy lives! This doesn't mean they don't have or won't make the time to help. However, it does mean that if you want them to come for the afternoon to sort medical papers or give you a ride to the doctor, you will do better to schedule the time in advance.

Bring up unpleasant subjects. Tell your children what your wishes are regarding things like burial plans and how much medical intervention you want if you are close to death. Even better, put your wishes in writing and see that they all get a copy. This can help ensure your wishes are honored and save your family members from arguing about what they each think you want if you are not able to offer an opinion.

Go ahead and burden them a little bit. Love, family, relationship... these wonderful parts of life include some aspect of mutual care and, yes, obligation. You would help your kids if they needed you. You are not a bad person if you need to call on them to help you once in a while.

Reprinted with permission from author Sarah M. Schurr and the Parkinson's Resources of Oregon November/December 2009 newsletter. ■

PROGRAMS PROVIDED BY THE ST. LOUIS CHAPTER OF THE AMERICAN PARKINSON DISEASE ASSOCIATION

One of the *Missions* of our Chapter 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. In the November edition we discussed research being funded. Now we would like to describe programs offered to enhance the quality of life for persons with PD and their families. Our next issue will discuss services offered by the St. Louis Chapter of the APDA.

Our *Vision* is to expand significantly services and education programs to better meet the growing needs. As the late cartoonist Charles Schulz said, "Life is like a ten-speed bike. Most of us have gears we never use."

Support Groups

One of the biggest contributions APDA makes to the PD community is creating a network of volunteer-led support groups. The benefits of peer helping peer are strongly supported by research, including improved knowledge of the disease, improved ability to cope with the disease, lower risk of depression, more positive outlook on life, and increased self-esteem.

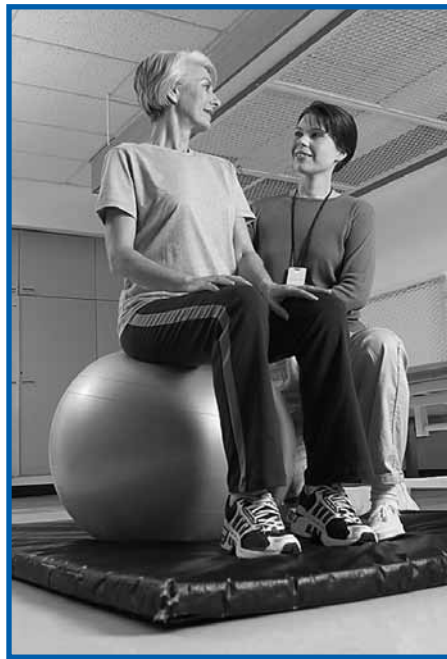
The format varies by location, but the goal is always to provide a safe, confi-

dential, welcoming place to come together. Groups offer PD patients and their caregivers the opportunity to exchange thoughts and share concerns and solutions to everyday living.

Groups meet monthly

Exercise Classes

Exercise empowers individuals with PD to feel stronger and more in control. Research further supports positive outcomes on personal outlook and mood. The medical literature has shown that medication and surgical intervention



alone are not adequate treatment for PD. Exercise, functional training and education are also integral parts of the management of the disease and its disabilities. As Robert N. Butler, a former director of the National Institute of Aging, once stated, "If exercise could be packed into a pill, it would be the single most widely prescribed and beneficial medicine in the nation."

Classes focus on exercises and activities to improve function, specifically balance, posture and functional mobility and are led by trained PT/OT.

Locations:

- Barnes-Jewish Extended Care (Clayton)
- Barnes-Jewish St. Peters Hospital
- St. John's Acute Rehab Hospital (West County)
- Garden Villas South (South County)
- St. Luke's Hospital (Chesterfield)
- Garden Villas North (Florissant)

1-hour class, meets once or twice a week

Aquatic Classes

In the water, an individual with Parkinson's can reduce the risk of falling and exercise safely. The buoyancy of the water supports the individual with Parkinson's while water-walking or turning a full circle. Several participants have commented that exercising weekly in the water has increased their ability to walk, turn in a circle, and maintain their balance. One participant commented, "I can walk in the water, but not on land." She also stated that she did not have to worry about falling while exercising because she was now able to exercise in the water without that worry. During the Winter 2009 session of water exercise, the balance of the individuals with Parkinson's was measured with a pre and post test of the Berg's Balance test. The Berg's Ba-

St. Louis Area	Missouri	Illinois	Specialty Groups
Clayton	Cape Girardeau	Alton	Care Providers Only
Chesterfield	Columbia	Bellefonte	DBS Group
Creve Coeur	Jefferson City	Carbondale	Newly Diagnosed
Festus/Crystal City	Joplin	Carmi	Young Onset
Florissant	Lake Ozark	Decatur	
Kirkwood	Rolla	Granite City	
Ladue	Ste. Genevieve	Greenville	
Oakland	Sedalia	Matoon	
St. Peters		Mt. Vernon	
South St. Louis		Quincy	
		Springfield	
		Vandalia	

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STL APDA PROGRAMS

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lance Scores concluded that the balance of the participants with Parkinson's remained the same or improved during the 10 weeks of 60-minute weekly water exercise classes. The participants of the classes have also reported an ability to maintain range of motion in their necks, upper extremities, and lower extremities. The water-exercise class has motivated several participants to keep moving, relax, and have fun improving their psychological well being.

The St. Louis APDA, ShowMe Aquatics & Fitness, the St. Charles YMCA, and Rainbow Village have collaborated to provide two water-exercise classes for individuals with Parkinson's since the spring of 2008. Classes are led by trained and certified instructors at pools specifically designed and accessible for our patients. We hope you join us for some fun in the pool!

Locations:

- Rainbow Village
- St. Charles YMCA

1-hour class, meets once a week for 10 sessions

Thursdays 2:00pm

Winter session runs from January 14 – March 18, 2010.

Dance Exercise Classes

(No openings at this time)

Preliminary data gathered from individuals with PD who learned to dance Argentine tango revealed significant improvements in balance, walking, and quality of life. This community-based dance program is an opportunity to study a yearlong dance intervention, and if the program proves successful, could be used as preliminary data to fund a larger, multi-site study of community-based dance programs for PD.

Social Dance

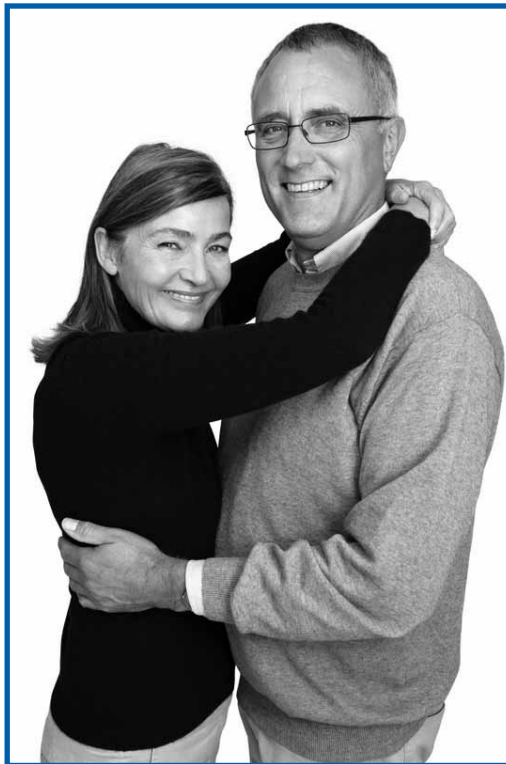
Dr. Oliver Sacks feels that “music is the prosthesis for the injured part of the brain. The pattern, timing and rhythm involved in music and dance will promote fluidity in movement, speech,

thought, and emotions.” Put on your dancing shoes and join us for this fun afternoon!

*Sunday, June 13, 2010, 2:00-4:00pm
@ Congregation Shaare Emeth Auditorium.*

PD 101

This class is designed to impart basic information about Parkinson's disease, available treatments and resources in our community. Participants receive printed material, a welcome packet,



Parkinson's Disease for Dummies by Tagliati-Guten-Horne and an exercise DVD, *Delay the Disease*, by David Zid.

PD101 is scheduled on an individual basis within two years of a PD diagnosis.

Wellness Courses

The Wellness Course is an education and support group of twelve persons with PD and their care partners who meet with the goal of helping individuals with PD and their family members develop skills and confidence in managing the everyday activities and relationships that may be challenging when living with PD. An occupational therapist with training in PD facilitates the weekly small-group discussions that enable members to share ideas for resources

and adaptations, express feelings, and problem solve challenges. The group members choose what topics to discuss each week; typical past topics were medication management, coping with physical and emotional changes, home safety, physical fitness, and long-term planning. The overall purpose of the Wellness Course is to enhance the quality of lives of individuals with PD and their family members through gaining confidence and skills in managing the consequences of the disease.

2-hour course, meets once a week for six weeks

Speech Classes

Parkinson's disease skews the individual's sensory perception, resulting in a soft voice in 89% of people with Parkinson's. Eventually there is a loss of muscle strength and physical endurance to speak at appropriate loudness. These classes incorporate practice and role play situations in conversational speech tasks produced at normal loudness levels in a “safe” environment.

Classes are led by LSVT trained and certified Speech-Voice Pathologists using the single reminder BE LOUD! to bring voices to improved, healthy and appropriate vocal loudness levels.

1-hour session, meets twice a month for three months

Speaker Series – Parkinson Education Programs (PEP)

This free speaker series with guest lecturers covers a wide variety of subjects such as Research Updates, The Importance of Exercise, Coping Strategies, Non-Motor Aspects of PD, Cognitive Aspects of PD, Deep Brain Stimulation (DBS), Lee Silverman Voice Treatment (LSVT), and Tips for Caregiving.

2-hour session plus questions & answers, meets once per quarter

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

WHERE THERE'S A WILL...

...THERE IS INCREASED HOPE FOR VICTORY OVER PARKINSON'S DISEASE!

A will is perhaps the single most important document you can own, although more than half of all Americans die without one. Only through a will and careful planning can you benefit the people and organizations you care about most in the exact manner you have intended. Don't think of your will only in terms of probate taxes, bequests and other legalese. This important document is primarily about people—your spouse, children, grandchildren, other relatives, close friends, and organizations that serve others, such as the American Parkinson Disease Association.

Many individuals have asked for advice on ways to include the APDA as a beneficiary in their wills. It goes without saying that such bequests are of great value to the APDA and play a key role in our ongoing efforts to improve the quality of life for persons with PD and their families.

The following language has been reviewed and is deemed a legally acceptable form for including such a bequest in a will:

"I give and bequeath to the American Parkinson Disease Association of Greater St. Louis, located at Campus Box 8111, 660 S. Euclid Ave., St. Louis, MO 63110 for discretionary

use in carrying out its aims and purposes, (the sum of \$ _____) OR (a sum equal to _____% of the value of my gross estate) at the time of my death under this will or any codicil hereto." (Please contact the St. Louis APDA for our federal ID number.)

Some additional bequest options would include the bequest of a specific object of value, shares of stock, proceeds from a life insurance policy, or the remainder of an estate after provisions of debts, general and specific bequests, and administrative expenses, including taxes.

Also, there are Charitable Remainder Trusts, which make annual payments to a beneficiary for a specific period of

time (including a lifetime), after which the trust remainder is transferred to another designated organization, and Charitable Lead Trusts, which work in the exact reverse order.

The most important aspect in considering or making any changes to a will is that the well-being of your own family occupies the top most position in your planning. And, for their and your protection, you should always consult an attorney about any changes you plan to make to your will.

Reprinted with permission from the Parkinson Research Foundation, Parkinson Disease Update quarterly publication, Fall 2009. ■

MAKING IT THROUGH TOUGH TIMES: BUILDING RESILIENCE

Linda O'Connor, LCSW (excerpts from David Rintell, PhD)

Getting a diagnosis of Parkinson's disease is a life changing event which starts people (both the person diagnosed as well as family members) on a journey full of challenges and uncertainty. But how you react to these challenges, how well you adapt to the changes and continue on with life can make all the difference in the world related to how you feel emotionally, how well you cope and the impact it has on your relationships. The quality of adapting well in the face of struggle is called **resilience**.

Resilience involves the ability to confront adversity and still find hope and meaning in life. It is having the capacity to "bounce back" from a difficult time feeling strengthened and more resourceful. Resilience is not a trait that people either have or don't have, rather it is a process involving behaviors, thoughts and actions that can be developed and strengthened. So the good news is that no matter what your age, your life cir-

cumstances or your PD symptoms, you can take steps to build your resilience so you can "weather" life's challenges.

Listed below are 10 ways to build resilience. You may already be doing some of these, but it never hurts to add on additional strategies. In this uncertain world we live in, we need all the help we can get!

1. **Make connections** – research (and common sense) tells us that people who have social support do better both emotionally and physically.
2. **Make achievable goals** – make them small and realistic. Figure out what you can change and what you need to let go.
3. **Take action!** – act on your goals, it gives a sense of accomplishment and capability and that feels good.
4. **Locate your strengths** – how did you overcome challenges in the past? What skills did you use? Everyone has strengths; you just have to sometimes remind yourself.

5. **Express gratitude** – it reminds you that something is good and changes your focus.
6. **Maintain hope** – give yourself permission to be hopeful; hope is justified (there's a lot of PD research under way).
7. **Keep things in perspective** – avoid blowing things out of proportion. Focus on what you can do instead of what you can't.
8. **Utilize your faith/spirituality** – having a connection to a community of faith, having a sense of something larger than yourself can bring comfort and peace.
9. **Give to others** – attend a support group, volunteer with the APDA Chapter, get involved with a community group; it's all good and changes your perspective.
10. **Humor works** – laugh at the silliness of life, find the humor in struggle, it really does lighten the load a bit. ■

TREAT YOURSELF TO A STICK OF CHEWING GUM

Early research indicates that chewing gum several hours a day may improve some of the speech and swallowing symptoms associated with Parkinson's by exercising the mouth. The researchers believe that chewing gum may help train Parkinson's patients to also move their tongues while eating and swallowing. "Gum acts as a sensory cue to train the system," says Dr. Mandar Jog of the London Health Sciences Centre



and Director of the Movement Disorders Centre in southwestern Ontario.

Chewing gum to exercise the mouth doesn't involve any extra hardware and is socially acceptable. Caution should be exercised in cases where patients are bedridden or found to be aspirating.

An added benefit is gum that contains xylitol fights off bacteria and will keep your teeth healthier. Also, because some of the medications prescribed for Par-

kinson's disease cause a dry mouth (xerostomia), another benefit to chewing gum is the stimulation of saliva, which further protects your mouth from cavities and forming plaque-like substances on your teeth (in addition to keeping your gums healthier). Dentists remind us to choose sugarless gum or check the label for the presence of xylitol.

Published in the November 2009 edition of the Houston Area Parkinson Society (HAPS) newsletter, HAPS Happenings. It is reprinted with permission from HAPS. ■

PRESCRIPTION ASSISTANCE PROGRAMS DIRECTORY

The programs below offer financial assistance toward the cost of prescription medications. Most of these organizations work on the patient's behalf with the drug companies, and may charge a small fee for their service.

- **Extra help with prescription drug costs**—You must be enrolled in a Medicare Prescription Drug Plan. www.ssa.gov/prescriptionhelp
1-800-772-1213
- **Patient Advocate Foundation – Co-Pay Relief**—Helps with co-pay cost for patients with insurance. Limited to specific diseases. www.copays.org
1-866-512-3861
- **Needy Meds**—An information resource to help people who can't afford to pay for their medications. www.needymeds.org (no phone helpline)
- **Rx Assist**—Provides a comprehensive listing of pharmaceutical company Patient Assistance Programs. www.rxassist.org
401-729-3284
- **Partnership for Prescription Assistance**—Provides assistance for low-income uninsured patients to get free or nearly free prescription medicines through existing Patient Assistance Programs. www.pparx.org
1-888-477-2669

- **Rx Outreach**—A low-cost, mail-order prescription drug program for low income families. www.rxoutreach.com
1-800-769-3880
- **Rx Help**—A prescription assistance company that helps qualified patients access and remain in a pharmaceutical Prescription Assistance Program. www.rxhelp4u.com
1-866-960-9497
- **Rx Hope**—A Web-based assistance program to help patients access pharmaceutical Prescription Assistance Programs. www.rxhope.com
1-877-267-0517

Missouri/Illinois Region Assistance Programs

- **Walmart \$4 Prescription Program**—Offering hundreds of prescription drugs and more than 1,000 over-the-counter medications at only \$4 per 30-day supply. Available at Walmart pharmacies.
- **Benefits Checkup**—A web-based service by the National Council on Aging that allows users to find and enroll in federal, state, local and private programs that help pay for prescription drugs, utility bills, meals, health care and other needs. www.benefitscheckup.org

- **Schnucks \$4 Generic Prescriptions**—Available at Schnucks Pharmacies offering more than 300 generic drugs priced at \$4 for a 30 day supply. Also, 7 different generic oral antibiotics free for up to a 21-day supply.
- **Walgreens Prescription Savings Club**—Offers discounts on more than 5,000 brand name and generic medications with over 400 generics priced at \$12 for a 90-day supply.
- **Illinois Cares Rx**—For Illinois Residents who meet certain income criteria. www.state.il.us/aging/lrx/cbrx/qualifications.htm#icrx-req
- **Illinois Rx Buying Club**—Discounts on brand name and generic prescription drugs. Savings average 20%. Card accepted at 50,000 locations nationwide, including 2,500 pharmacies in Illinois. Mail order service offers greater savings. Drugs on preferred drug list are discounted further. Must meet income requirements. www.illinoisrxbuyingclub.com
- **MO Rx**—Works with all Medicare Part D plans. Pays 50% of your deductible, 50% of your co-pays (including during the coverage

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TAKIN' IT TO THE STREETS!

Think back, if you will, to what it felt like when you were first diagnosed with Parkinson's disease, or what it felt like to learn that one of your parents or siblings had been diagnosed. I'll bet you can still recall what went through your mind or what action you took. I receive calls every week from people who have recently been diagnosed and are anxious for knowledge. The call might be from a rural resident who is so baffled as to why people think he has been drinking when he speaks with slurred speech, resultant from his Parkinson's and not from being intoxicated. Or the call I receive from a nursing home resident pleading with me to please send out a DVD that the staff can watch to become better educated about the importance of giving him his medication on time. We hear about the staff coaxing him to move, which will not result in movement when his feet feel like they are stuck in concrete during a "freezing" episode. And he tires of explaining why the battle with constipation is never ending and does not always respond to the usual treatment of such.

Do these frustrations sound familiar? Do you also hear stories about misdiagnoses and improper treatments? We hear them—and hear them all too often. Feedback from members of the St. Louis Parkinson's community was carefully considered when the Board of Directors spent six weeks in strategic planning sessions. The Board recognized the necessity of significantly expanding patient services and education programs in response to the growing and unmet needs of patients, families and medical personnel. The planned expansion is both geographic and vertical - encompassing more rural areas and more professional caregivers. We will target physicians as well as paraprofessionals working in senior living facilities and home health agencies. In 1998, the St. Louis APDA, then under the direction of Susan Levin, produced a video about the unique needs of Parkinson's patients entitled *Caring for a Nursing*

Home Patient with Parkinson's Disease. It continues to be utilized in nursing homes around the country, as well as in training for others who care for PD patients, but an update is essential. This tied in nicely with the Board's vision "to expand significantly patient services and educational programs to better meet the growing and unmet needs while maintaining its commitment to fund Parkinson's disease research."

Enter a gerontology student who has a parent suffering from Parkinson's disease. In conjunction with a class project, we agreed that she would write a grant request, and the idea of Takin' It to the Streets was born. The "It" is education about Parkinson's disease and the "Streets" represent a much wider audience. The proposal involves creating an instructional media set to be freely distributed to 3,500 carefully selected physicians, libraries, support groups, nursing homes, senior centers, and others. It will first focus upon underserved rural areas in Missouri and southern Illinois. A newly produced DVD will include interviews with movement disorder specialists, slides responding to frequently asked questions, and illustrations of care techniques. Segments of the DVD will be directed to medical personnel and/or patients and their families. Booklets, web links and other resources will be shared on a CD.

So what does that mean for you? This project is budgeted at \$60,000—only about \$17 per completed and mailed instructional media set. If ten people view each DVD, just think of the benefits gained for the cost of \$1.70 per person! Your mission, should you choose to accept it, is to think of ways we can fund this project. Perhaps you'd like to consider being a grantor or donor? Please help us help others. Help us encourage early and accurate diagnoses. Help us share information about treatments and life-style modifications that can delay the disease and improve qual-

ity of life for all concerned. What we learn about this disease deserves to be shared with all patients and all caregivers, especially those with limited access to existing resources.

Consider sending a donation in the blue tribute envelope attached to this newsletter, or through our website, www.stlapda.org. Mark your donation for this purpose, and help us take our wonderful resources "to the streets"—and gravel roads of Missouri and southern Illinois. If you know of an individual, a business owner or corporation who may wish to provide a grant to make this project a reality, please have them contact Debbie Guyer at 314-362-3299 or by email at guyerd@neuro.wustl.edu. It will be an investment with untold returns. ■

PRESCRIPTION ASSISTANCE PROGRAMS DIRECTORY

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gap and beyond) of your Medicare Part D plan. Does not pay for the Medicare Part D plan's monthly premium. Uses the formulary of the Medicare Part D plan. Works in conjunction with Missouri HealthNet. Covers up to a 31-day supply for each prescription. Can use any MO pharmacy that works with your Part D plan. No mail order services.

morx.mo.gov/pages/benefits.htm

Drug Discount Card Programs

- www.needymeds.org
- freedrugcard.us
- www.scbn.org/about_us.html
- www.freemedicine.com
- www.yourrxcard.com

Modified from Salt Lake City, Utah, Information and Referral Center, Summer/Fall 2009 Parkinson's News. ■



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.

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	Gerry Neely, RN	573-815-3554
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 Becky Simmons	314-355-6100
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday 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 noon		2-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	5:30 PM	Patsy Dalton	573-964-6534
Rolla	Phelps	Rolla A 2:30 PM 1101 McCutchen	4th Thursday	1:30 PM	Mary Harlan Richard Wagoner	573-364-6820
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	DBS Patients Sunrise on Clayton Sr. Living 7920 Clayton 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

**Pre/Post DBS
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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.

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	First Christian Church 504 Bohlever Dr.	3rd Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
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	Sarah Busch Hospital 500 Health Center Dr.	Last Tuesday	1:00 PM	Kay McDade	217-258-4040
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



EXERCISE CLASSES

Our Exercise Classes meet once a week or otherwise as noted.

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 Leigh, 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

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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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DELAY THE DISEASE – FUNCTIONAL FITNESS

David Zid

Balance

Maintaining balance is crucial with Parkinson's disease. It is important for fall prevention, improving your ability to walk and pivot, and will boost your confidence as you navigate through crowds and obstacles. As you work with this exercise plan, practice making the moves difficult for you, challenge yourself. Remember, work really hard while performing these exercises so that when you are in the real world, everything will be easier. You may need a partner for a few of the following. Good luck, and have fun with these. ■

3 SECOND HEEL-TOE WALK

Slowly walk using a normal stride length, but focus on a very slow step with your heel striking first. Start with your right foot. It should take 3 seconds from the time that your right toe leaves the floor until the right heel touches the floor. This will actually allow you to balance on one foot in between steps. Concentrate on using the entire 3 seconds for each step; don't hurry. Try to perform this walk for 30 seconds, working up to 2 minutes.

BALANCE WITH FLOOR TAP

Stand with both feet close together. Squat down slowly, touch the floor in front of you with one hand, then return to standing position. Repeat 5 times using each hand. Again with both feet close together, hold a weighted ball or other light weight in your hand, squat down and place ball on the floor then return to standing position. Now squat down to pick up the ball. Repeat 10 times.

ONE LEGGED FLOOR TAP (ADVANCED)

While balancing on one leg, squat down slowly, touching the floor as above, and return to standing position. If this is too difficult, place a chair in front of you and squat down and touch the seat of the chair while maintaining balance on one foot. Repeat on both legs 5-10 times.

ADVANCED FLOOR TAP

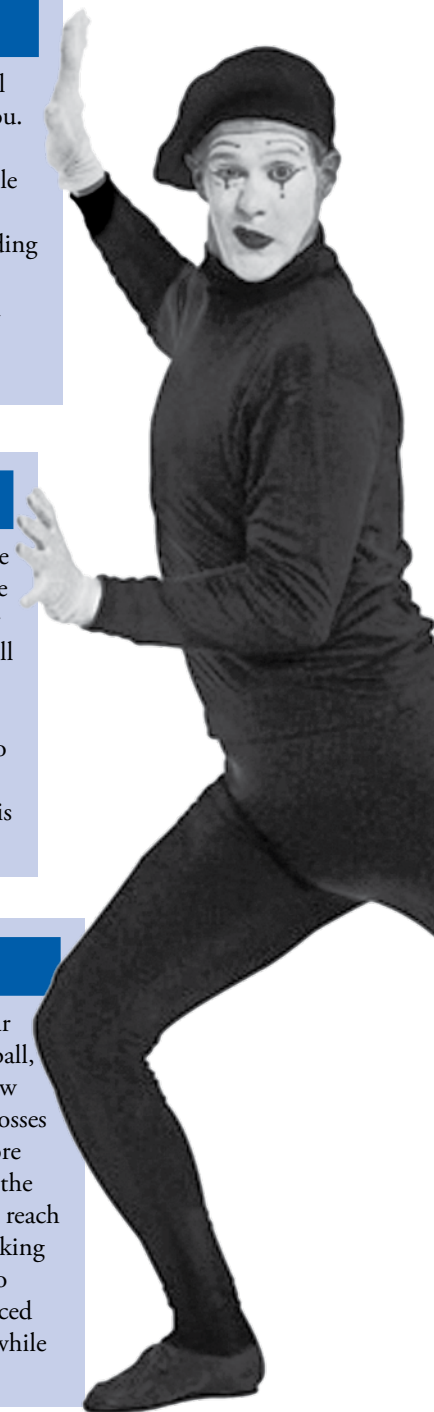
If you really want a challenge, place a ball or light weight on the floor in front of you. While balancing on one leg, squat down, pick up the ball and stand back up. While maintaining balance, place the ball back down onto the floor, then return to standing position. If this is too difficult, place the ball on a chair in front of you to perform this exercise. Repeat on both legs 5-10 times.

PARTNER BALANCE CHALLENGE

Stand with your back to the corner. Using an exercise band, a rope or even a long towel, hold one end while your partner grabs the other end. Standing with your feet close together and slight tension on the band, pull against each other attempting to pull your partner towards you and off balance. Whoever can maintain their stance and not fall off balance is the winner. Go 3 rounds with your partner; have fun but perform in a safe environment. For a more advanced form of this exercise, try performing while standing on one foot.

PARTNER BALL PASS

Stand about 3 – 5 feet apart from your partner. Using a weighted medicine ball, or a lightweight playground ball, throw the ball to your partner. After a few tosses directly at your partner, make this more difficult by throwing it to one side or the other so as you catch you will need to reach for the ball. Throw low and high, making your partner stretch. Have fun, but do this in a safe place. For a more advanced form of this exercise, try performing while standing on one foot.



WALKING STRATEGIES FOR PEOPLE WITH PD

Kevin Lockette, PT

Okay, you can hear each and every step you take and the front under soles of your shoes are worn thin. Often times you just get going and you can't stop. Your walking may look like this: shuffling feet, knees are bent the entire time, slumped posture, and no arm swing.

There are also multiple gait abnormalities of lesser degree that may show up first. One of the first notable gait changes is loss of arm swing on one side. Other abnormalities include a stiff-legged gait. This is basically when your knee stays stiff or you leave it or drag it behind you; however, if you were instructed to march you could flex and bring the leg forward. This is just another example of the need for conscious thought to move. With advancing PD, you can experience a "festinating gait." This is when your walking speed uncontrollably quickens and can result in your breaking into a shuffling run in an effort to avoid falling. With Parkinson's disease, there is trouble not only with initiating movement but also terminating movement (festination). This article will give you some strategies to control and improve your gait (walking).

Conscious, Purposeful Movement

Regardless of your progression of PD, there are simple strategies that you can use to improve your gait and decrease your risk of falling as your PD progresses. You have been hearing much about purposeful movement and as you can guess, walking is a great place to apply it. You can no longer rely on your automatic pilot for movement. Basal Ganglia is responsible for automatic motion in learned motor tasks and this is no longer functioning properly with PD. The ability to move is not lost. Instead of relying on the depleted basal ganglia for automatic movement, you have to bypass it (basal ganglia) and use the fronto-cortical pathways which are not affected by PD but require con-

scious thought. In other words, prior to Parkinson's disease, you did not have to think to move, but now you do.

Value of External Cues for Walking

Studies have indicated that different types of cueing can aid movement with PD. There are four basic types of cues: Attention-Conscious Movement, Auditory-Rhythm, Visual-Marker/Target and Tactile-Sensory Stimulation. What may be helpful is talking to your body. Actually tell the legs and arms when and how to move. You are simply cueing yourself. This technique brings your movement to a conscious level. Rhythmic auditory cues can improve your walking pattern. This can involve timed auditory cues such as clicks, beats or taps given at specific intervals for learning a sequential activity. There have been multiple studies that have shown improved walking patterns using this technique. Some people have practiced walking with a metronome to cue weight-shifting and stepping. Some folks that I have worked with will hum or click a rhythmic pattern with their tongue to self-cue their walking pattern. The use of music can assist in more smooth, less restricted movement. The bottom line is that you can improve your gait and general movement with external cues. It is a matter of finding out which cue works best for you.

Another effective training tool for improved gait is to use two broom sticks, hiking poles or two canes. Now you will perform a 4 point walking pattern which goes like this: (1) stick, (2) opposite leg, (3) opposite stick, (4) opposite leg. It helps to talk to your body: "Arm, Leg, Arm, Leg." With each step, attempt to get your heel down first while your knee is fully extended. The "four point gait" mimics the normal gait pat-

tern. Advancing the pole with one arm simulates arm swing while advancing the opposite leg simulates a reciprocal gait pattern that promotes pelvic rotation. One reason why this technique is effective is that not only does it force a normal walking pattern, but it also forces purposeful movement which can train or retrain you to walk.

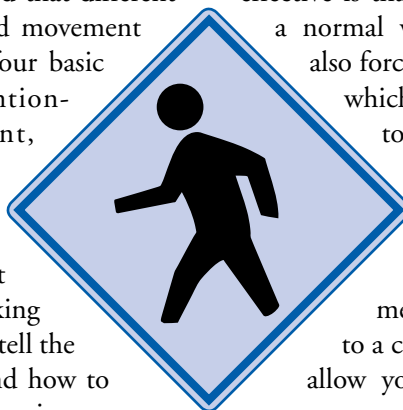
The four point gait can also be a strategy to combat freezing.

The purposeful movement brings your walking to a conscious level which can allow you to regain control of your movement. Some of my patients will pull out their "imaginary" canes and use the four point walking pattern to unfreeze or to initiate walking. This is especially useful when having to get up in the middle of the night to use the restroom or during the wearing off periods of your medication. Below are other walking strategies that you may find helpful.

Walking Strategies

- Always initiate walking with a purposeful first step. It is often helpful to train yourself by taking the first step with the same leg each time.
- Start walking with a marching pattern. I call this the "British Soldier." After a few steps you can settle into a less obvious gait pattern. The marching pattern forces you to have a reciprocal arm swing as well as a good leg swing to decrease leg drag or the tendency to shuffle your feet.
- If shuffling of your feet occurs, purposefully attempt to get your heel down first with each step. Just focusing on heel strike assists in keeping your center of gravity over your base of support and gives you

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NEW FACULTY JOIN THE MOVEMENT DISORDERS CENTER

Joel S. Perlmutter, MD

Because of the many interactions our readers across the state and in Illinois have with the neurologists at the Movement Disorders Center at Washington University, and having read in the November, 2009, edition of the LINK about the research being conducted at the APDA Center for Advanced Research, Dr. Perlmutter has written an introduction to the new faculty you may encounter as you participate in clinical trials.

Dr. Allison Wright Willis has been promoted to Assistant Professor of Neurology and will continue her research investigating environmental exposures and how they might contribute to the development of parkinsonism. Dr. Wright Willis recently completed her fellowship in Movement Disorders under the mentorship of Dr. Brad Racette and she was awarded a new mentored career grant to continue her research. She is an outstanding clinician, caring for many of our patients with PD.

Dr. Marc Diamond joined our faculty as an Associate Professor of Neu-

rology. He came from the University of California at San Francisco and currently focuses his research on the molecular changes in brain proteins and how this may contribute to the development of neurodegenerative diseases – a term that includes PD. He will start seeing patients in the late winter after time to set up his lab at Washington University.

Dr. Erin Foster has also been promoted to an Assistant Professor of Occupational Therapy and her work centers on understanding how various treatments of PD affect an individual's ability to perform activities of daily living. She had completed a fellowship under the mentorship of Dr. Tamara Hershey, a neuropsychologist in our group. Dr. Foster also has been awarded a new mentored career grant to continue her research.

We also have been lucky to recruit **Dr. Meghan Campbell** to return to our group as an Assistant Professor. She had completed her fellowship with Dr. Tamara Hershey and then moved to

Marquette University as an Assistant Professor in Psychology. However, with a persistent sales pitch we were able to convince her to return. She will primarily focus her efforts on studies of deep brain stimulation and on dementia in PD.

We were sad to say adios to **Dr. Diego Torres** who completed his fellowship with me and now is an Assistant Professor at the University of Nebraska where he works in Movement Disorders. Nebraska gained a new star.

It is important to recognize that a critical part of research is training new investigators. These new faculty demonstrate, in part, our effectiveness in this training role. Without question, these rising stars will enhance our research studies of PD. We continue to make progress on many fronts in our research into the causes, mechanisms and treatments for the disease. Together, we will continue to make progress in our fight against PD. ■



HELP WANTED!

FASHION SHOW COMMITTEE CHAIRPERSON POSITION OPEN

We are in need of a volunteer Committee Chairperson for the 2010 Fashion Show taking place October 11. This annual event regularly draws crowds of 400 people and includes a luncheon, fashion show, raffle and silent auction. The Fashion Show Committee Chairperson is responsible only for the fashion show portion of the event, and must be a strong leader. Duties include:

- Working with clothing boutiques to select featured fashions
- Organizing models and escorts
- Designing fashion runs
- Writing talking points for emcee
- Participating on the event committee

If you or someone you know is interested, please apply by sending your previous experience with fashion show and event planning to Debbie Guyer—guyerd@neuro.wustl.edu or **Campus Box 8111, 660 S. Euclid Ave, St. Louis, MO 63110**. Please respond by April 1, 2010.

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

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SAVE THESE DATES!

Saturday, April 17

**Spring PEP Meeting with Dr. Larry Elmer,
David Zid, and Jackie Russell**

10:30 am-2:30 pm (lunch provided)
Sheraton Westport Chalet
Sponsored by TEVA Neuroscience

Monday, May 17

**Nat Dubman Memorial Golf Tournament
Honorary Chairperson John “Mo” Mozeliak,
GM St. Louis Cardinals**

Lake Forest Country Club
10:00 am Shotgun Start

Sunday, June 13

Social Dance

2:00 pm-4:00 pm at Congregation Shaare Emeth
Sponsored by Jack Strosnider

Monday, October 11

Fashion Show & Luncheon

Sheraton Westport Chalet

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.**

WALKING STRATEGIES

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improved balance while lessening the chance of an uncontrollable gait.

- If you continue to shuffle, STOP and restart with a purposeful step. Try not to work through the shuffle as it may lead to a fall. Allow your arms to swing freely. If you have one stiff arm, you can carry an object or swing a purse or bag with the stiff arm. The additional weight along with momentum can make it easier to engage the “stiff” arm in your walking pattern.
- Turn corners in a wide arc. Avoid crossing your feet over each other when turning.

By implementing these simple strategies you will be able to improve your gait and lessen your risk for falls.

Adapted from the book/DVD, Move It—An Exercise and Movement Guide for People with Parkinson's Disease. ■