LiNK St.Louis APDA

APDA
www.stlapda.org

May 2012: Vol. 26, Issue 2

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

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.

IN THIS ISSUE

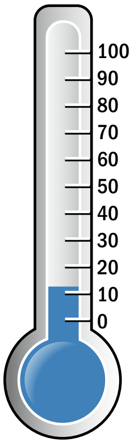
NEWSLETTER DISCLAIMER

"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."

ONLY 11.8%

Deborah Guyer, Executive Director, Greater St. Louis APDA Chapter and Coordinator of the APDA Information & Referral Center

I always try to put something uplifting on the front page of newsletters, but in this issue, I may have to make an exception. We purchased a new database system in order to improve our efficiency in handling all the patient services, fundraisers, and donations we receive. And, my computer-savvy assistant, Elaine, finally figured out how to write a query which would reveal how many people who receive our newsletter actually have contributed monetarily to the St. Louis APDA. Well, Elaine tells me that of the 7,258 people who regularly receive our quarterly newsletter (most have requested it for themselves or a family member, or may be a donor making a contribution within that quarter who also receive one issue), only 857 recipients have actually contributed in the past. That is 11.8% of you reading this newsletter. Does that figure surprise you? It did me!



So, what can I do to motivate you to send a gift to the Greater St. Louis APDA? You will want to see the recently released, *The Parkinson Journey*, our new DVD resulting from the Takin' It to the Street campaign and you will recognize the need. There is hope for finding causes which will lead to a cure, but research costs money. We provide so many varied patient services, but they aren't always free to our organization (although in many cases, hospitals and care centers have partnered with APDA in an effort to provide professional staff and space in their facilities for exercise and support groups).

Together, we can make a difference. Consider participating in our upcoming fundraiser. For instance, even if you don't golf, you can sponsor a hole on the course in our golf tournament. See the article, "Optimism…It's Contagious," for additional ideas. Our dollars have enabled researchers at Washington University Medical School to conduct the first research on incidence and prevalence of Parkinson disease in the U.S. using Medicare data, discover the benefits of Tango dance on PD, and detect a different kind of dementia in Parkinson patients. It has funded research being conducted at St. Louis University which postulates that an accumulation of a toxic product of dopamine, DOPAL, is toxic to neurons in the brain and leads to PD. This observation provides an important link to the etiology of Parkinson disease. If DOPAL is the culprit, we may now have a target to which we can take aim, and perhaps develop a therapeutic agent which can slow Parkinson disease.

This newsletter proposes ways that you, individually, can join many others in fundraising for Parkinson's disease. Please read about the Optimism campaign, and join us in our efforts. You may also choose to participate in a newly established campaign, **Optimism 500**, in which you will be recognized for contributing $500 or more during a calendar year. Your participation will result in invitations to VIP special events, as well as recognition in our quarterly newsletter.

I look forward to reporting that 11.8% of "members" contributing to support our programs and services and fund research has increased significantly by the time you are reading the next newsletter. I wish I could come up with something creative or catchy to get your attention so that this message is even more effective, but my sincere invite will have to suffice for now. We have much to do and the clock is ticking. 132,000 new Parkinson cases will be diagnosed this year. ■

APDA INFORMATION & REFERRAL CENTER
Deborah Dalin Guyer, MA, Coordinator
guyerd@neuro.wustl.edu
Elaine Dreher, Program Coordinator
drehere@neuro.wustl.edu
Campus Box 8111 • 660 S. Euclid
St. Louis, MO 63110
314-362-3299 • 314-747-1601 (fax)
Office Hours:
Monday–Friday 7:30 AM–4:00 PM
www.stlapda.org

ST. LOUIS CHAPTER SATELLITE RESOURCE CENTER
1415 Elbridge Payne, Suite 168
Chesterfield, MO 63017
636-537-5455
Call to make appointment.

ST. LOUIS CHAPTER APDA BOARD OF DIRECTORS
Rebecca Daming, President
Tom Mackowiak, 1st Vice President
Bob Goldsticker, 2nd Vice President
Don Carlson, 3rd Vice President
Rebecca B. Farris, Secretary
Brian Hantsbarger, Treasurer
Matt LaMartina, Past President

MEMBERS AT LARGE
John R. Basilico
Bill Billings
Patsy Dalton
David Dankmyer
Brook Dubman
Joseph Marchbein
Robert Sanderson
Jack Strosnider
Lynda Wiens

DIRECTOR EMERITUS
Susan B. Levin

EXECUTIVE DIRECTOR
Deborah Dalin Guyer, M.A.

MEDICAL DIRECTOR
Joel S. Perlmutter, MD

NATIONAL AFFILIATION
APDA • 135 Parkinson Ave.
Staten Island, NY 10305
800-223-2732

EDITOR
Deborah D. Guyer

CONTRIBUTING EDITORS
LInda Clark
Elaine Dreher
Betty Hayward

APDA
TO EASE
THE BURDEN
TO FIND THE CURE

BOARD BRIEFS

Matt LaMartina, APDA Board President, has passed the baton to **Rebecca Daming,** who has taken over the role as President of the Board effective March 2012. Becca has served on the Board since 2008. We want to express our gratitude to Matt who has served the Board well in this capacity for seven years. Matt will remain as Past-President on the Executive Board and continues to be very involved with the Dubman Memorial Golf Tournament, which will take place on May 21. Matt was responsible for securing John 'Mo' Mozeliak as our Honorary Chair for the past several years.

Stan Wilensky, APDA Board member, has resigned his position due to health reasons. Stan has served on the Board of Directors since 2001 and was the driving force behind the creation of the DBS Support Group, following his surgery 12 years ago. He has facilitated the group since its inception, and he and his wife, Donna, co-facilitate (with Steve Balven) the DBS monthly support group. Stan has also served as a strategic member of the golf committee and both he and Donna remain dedicated auction gift solicitors.

It is with deep sadness that we mourn the passing of **Bernie Frank**, long-term APDA Board member (2004-2011) and active member of PAN. Bernie passed away in March and is already missed by so many people. The Frank family has taken comfort in the generous and thoughtful expressions of sympathy offered by friends and family and in the knowledge that these memorial contributions will help us find causes and a cure for Parkinson's disease.

We welcome new APDA Board member **John Basilico**, who joins us this month and who many of you know from his article in the February newsletter, "I'm a PD Newbie." John has many skills and talents which we have already put to good use! ■

Remember to get your clubs out

AND JOIN US AT THE
MAY 21st GOLF TOURNAMENT,
BENEFITING THE
ST. LOUIS APDA.

Honorary Chairman: John Mozeliak,
General Manager, St. Louis Cardinals

Dinner-only option available!

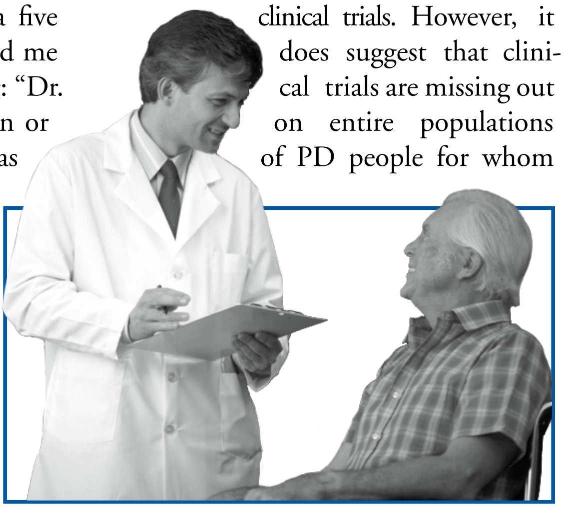
Optimal Care in PD: Does Physician Specialty Make a Difference?

By Allison W. Willis, MD, Assistant Professor of Neurology, Movement Disorders Section, Washington University School of Medicine

Last year, I had a new patient come to see me for a second opinion about her PD management. As is typical for a newly diagnosed person, she brought an entourage of loved ones with a list of questions, which I love. As we were working through their questions at the end of the visit, I asked how far she had traveled for her appointment with me, as I did not recognize the town listed on her address information sheet. She paused, and then told me that she lived in a rural area five hours away. What she said next led me to doing the study I am presenting: "Dr. Willis, there are no neurologists in or near our town. With the price of gas being so high, our church had a fundraiser to help us with the gas and hotel money so we could come today." It's true; there is a neurologist shortage almost everywhere in the country, rural and urban areas alike. Physicians with specialty training in Internal Medicine and Family Practice, therefore, find themselves seeing a lot of neurological problems. And although that probably works fine for common neurological complaints or symptoms like headache or dizziness, Parkinson's disease (as you know) is a different animal altogether. It is progressive, with many types of symptoms affecting movement, mood, thinking, and autonomic function. Then, there are those pesky motor fluctuations that occur later in disease- wearing off, dose failures, and dyskinesias. I wondered, "Who is taking care of the nation's PD population, and does that make a difference in some outcomes?"

To answer these questions, we studied all (over 130,000) Medicare beneficiaries with a new diagnosis of PD in the year 2002, and determined who the primary PD physician was. We then followed them for six years, and looked at nursing home placement, hip fracture, and survival.

Only about half of Medicare beneficiaries with PD see a neurologist; the rest are cared for by physicians in other specialties. We found that younger white men who live in urban areas were most likely to see a neurologist for their PD care. This was not unexpected, as this is the population that is most often present in my specialty clinic, and is also the population most involved in clinical trials. However, it does suggest that clinical trials are missing out on entire populations of PD people for whom drugs and therapies have failed, which may in fact work for others (we have not seen). It may also mean that women and Asian, Hispanic and African-Americans with PD may not have access to or are not receiving state-of-the-science (gold standard) PD care. We also found that people who received neurologist PD care were 20 percent more likely to be alive at the end of the study period, less likely to be in a nursing home after the first year, and less likely to have a hip fracture in the first year.



While it may be suggested that this study means all people with PD need a neurologist, and that neurologist care is the reason for these improved results, I think the data is too preliminary to draw that conclusion. There are other scenarios that could explain part of our results. For example, a person who is very sick with heart failure or diabetes and has PD may be too sick to see a neurologist and a cardiologist and his or her primary care doctor. Someone like this who has other medical conditions that are more severe than their PD would be less likely to need a neurologist for PD care, and more likely to die (from their heart problems). And, it is possible that people with a PD lookalike (the much rarer, but more rapidly progressive diseases that include MSA, PSP, and CBD) are being diagnosed as PD by non-neurologists. Finally, some people with PD may choose to not follow through with a referral to a neurologist, or get sick before they can go. Consider this other alternative explanation: People who follow through with a neurologist referral may follow other medical advice more as well; they may simply take better care of themselves by exercising, eating well, and getting recommended screenings. Within families or communities, women may be more likely to push their spouse with PD to see a specialist. Cultural factors may influence whether a person feels it is appropriate to seek a second opinion from a specialist.

While this data is not strong enough to support a policy change yet, it does open the door for more studies to better understand all of the ways people with PD can receive the best care possible, and highlights the comprehensive approach to PD research at Washington University, much of which is supported in part by the Greater St. Louis Chapter of the APDA. Future studies of mine will use Medicare data to investigate how non-PD diseases affect survival and use of specialty care, identify avoidable medical problems in PD and finally, to develop methods to assess (and if necessary), improve how PD care is delivered in areas of neurologist shortage. ■

LEE SILVERMAN VOICE TREATMENT (LSVT®) BIG AND LOUD THERAPY

TREATMENT FOR SPEECH AND MOVEMENT DISORDERS FOR INDIVIDUALS LIVING WITH PD

M'Aggie Maranzana, MOTR/L, CLT, MSCS, MBA Lead Therapist, Missouri Baptist Outpatient Rehabilitation

There is now evidence-based treatment that addresses the most common symptoms associated with Parkinson's disease. The LSVT BIG and LOUD therapies are designed to address the speech and movement disorders that often follow a Parkinson's diagnosis. These highly specialized and intensive treatment programs target the motor, sensory, and cueing problems that have historically made Parkinson's disease symptoms difficult to treat.

Disorders of the motor system contribute to rigidity; slow, small movements; and tremors. Decreased muscle activation during speech can lead to reduced breath support, reduced vocal loudness, and reduced clarity of speech. Likewise, this motor system deficit compromises recruitment of larger muscles used for walking and other daily activities often resulting in small, shuffling steps; freezing (poor initiation of movement); or inability to stop movements.

Individuals with Parkinson's often struggle with faulty processing of movement feedback. Because of this deficit in sensory processing, smaller, slower movements begin to feel normal. Likewise, soft speech begins to sound normal. They are unable to recognize when their movement amplitude or vocal volume is reduced. This often leads to frustration on the part of the family and the individual. The individuals feel that they truly are speaking at a normal volume while their families are constantly asking them to speak louder!

Another contributing factor is that individuals with Parkinson's are unable to cue themselves to change their volume or the size of their movements/steps. This directly relates to the sensory processing deficit. If what they are experiencing "feels normal," that internal cue to self-correct will be absent. Research has shown that external cues do have a positive impact on improving speech and movement impairments in people with Parkinson's. LSVT BIG and LOUD both incorporate the use of external cueing and exaggerated movements or vocal volume. The intent is not to teach the individual to shout or to constantly take large steps, but to assist the individual with the recognition that neither their current state nor the exaggerated treatment state is "normal." It is to recognize that "normal" lies somewhere in between.

Both the LSVT BIG and LOUD programs consist of 16, one hour, individual 1:1 therapy sessions over a four week period. Each program is tailored to the individual's interests, needs, and abilities. These programs have been designed to help the body relearn and accept volumes and movements that are actually within normal limits resulting in improved independence, safety, communication, and participation in everyday activities. ■

WHAT IS PLANNED GIVING?

David S. Dankmyer, JD, LLM

Planned giving is the integration of your personal, financial, and estate-planning goals with lifetime charitable giving. Planned giving, by definition, requires forethought. Making a planned charitable gift usually requires the assistance of the charity and/or a knowledgeable advisor such as an attorney, financial advisor, or CPA to help structure the gift. However, this does not mean it has to be complicated!

Planned gifts come in many sizes, shapes, and forms. They can be made with cash, but many planned gifts are made by donating assets such as stocks, real estate, art pieces, or business interests—the possibilities are endless. Planned gifts can provide valuable tax benefits and/or lifetime income for you and your spouse, or other loved ones.

Examples of Planned Giving

- Bequest
- Life Estate Reserved
- Charitable Remainder Trust
- Gift Annuities
- Charitable Lead Trust

The most frequently made planned gifts are bequests to charities made through your estate documents. Other popular planned gifts include charitable trusts and charitable gift annuities made during your lifetime. The outright bequest is the simplest type of planned gift to make. You can simply leave property or part of your estate to the APDA in your Will or Revocable Trust. You can also change beneficiary designation of certain property (such as an IRA) to name the Greater St. Louis APDA as the beneficiary of all or part of that property.

A Bequest can be specific as to the property transferred, amount, or a percent of the residual. For example:

continued on page 8

OPTIMISM…IT'S CONTAGIOUS

With optimism, people come together to raise money, see the positive on a difficult day, lift someone's spirits, be encouraged to take action, and move closer to a cure. All across the country, people are teaming up to reach a common goal: to "ease the burden and find a cure" for Parkinson's disease. Participating in the American Parkinson Disease Association's Optimism campaign allows you to spread hope, confidence, and a positive vision for the future, while increasing awareness about Parkinson's disease; raising money for education and support services; and helping to find a cure. Optimism events bring people together, empowering them to take action, and inspiring them to make a positive impact.

Organize an Optimism Event Today…It's Easy

Activities designed and run by volunteers to raise money on behalf of a specific nonprofit organization are growing in popularity today because they're personal, flexible, and FUN. Be as creative as you want with your event: Do you love to hike or bike? Maybe you're a bowler or a dancer. With your individual Optimism event, you choose the activity you want to do. Then invite friends or family to join you and start collecting donations today!

Ways to FUNdraise and Spread Optimism

There are many ways that you can raise money for the APDA – you just need to get a little creative. To get you started, we've compiled a list of individual and group fundraising ideas. Let people know that their donations are going to support a very good cause! Hold the event in honor or in memory of a loved one or dear friend. Even have a picture! People will relate to your cause and will more readily donate. Then, when your event is in full swing, remember to take pictures because we would love to share one of your photos in our newsletter.

House Party FUNdraisers

Charge an admission or ask for a donation at the door; for parties with games, the winnings are donated. Always remember to have a gift for the winner to keep the competition and excitement level high.

- Texas Hold-em party
- Wine-tasting party: If you don't want to do this yourself, there are companies that will come and donate a percentage of their profits from the people who buy their wine.

American Parkinson's
OPTIMISM

- Card party/Bunco party
- Garage sale: Ask your neighbors to clean out a closet and donate the items to your sale.
- Block BBQ party or competition: Ask your neighbors to join you in a friendly BBQ competition.
- Pampered Chef, Tupperware, or another company: Many companies will donate a percentage of the profit from that night's show.

Work FUNdraisers

- Dress-down day: In exchange for a donation, everyone can dress casually for the day.
- Office pool: Let everyone know that their entrance fee for the pool will be a donation, but offer the winner a prize to keep the excitement level up.
- Change jar: Have a change jar in a high traffic area. Maybe offer a piece of candy in exchange for a donation.
- Early Riser Breakfast: Bring or make breakfast for your co-workers. Ask for a small donation in exchange for starting their day off right.
- Matching donation: Many companies will match your donation to the APDA.

Community FUNdraisers

- Bake sale
- Craft sale
- Pancake breakfast: Remember this does not always have to be a morning event. Everyone loves breakfast for dinner!
- Chili dinner
- Clothing store/Boutique/Hair Salon/Fast Food restaurant: Many companies will donate a percentage of the day's receipts to a charitable organization. Remember to advertise this event amongst your family, friends, and colleagues.

Kids/Grandkids FUNdraisers

- Lemonade stand
- Gaming party: Ask your friends to participate in a Rock Band, Guitar Hero, Dance Party, or WII tournament. Collect entry fees, and secure a prize for the winning team.
- Yard services
- Dog walking service
- Babysitting
- Car wash

Higher Profit FUNdraisers

- 5K Run/Walk
- Dog Walk
- Trivia night
- Bingo
- Bowl-a-thon
- Tractor Pull
- 50/50 Raffle

continued on next page

PREPARING FOR YOUR NEUROLOGY APPOINTMENT: HELPING YOUR NEUROLOGIST TO HELP YOU!

Diane L. Church, PhD,
Coordinator APDA Parkinson's Center at Dartmouth-Hitchcock Medical Center, Lebanon, NH

On your mark!

An appointment with your neurologist will be most productive if you are prepared to share your information and concerns. Here is a checklist to help you get organized.

Get ready!

- ☑ If this is your first appointment, ask the neurologist's office what types of **information** you should bring. These may include office notes from other doctors, MRI or CT images of your brain, and lab reports.
- ☑ Medication list: Document all prescription **medications** (including non-Parkinson's drugs), over–the-counter medications, **vitamins**, and **supplements**; **dosages**, when medications are taken; and when you first start taking each. Are there any medications that you were on in the past that were discontinued? Have you experienced any **side effects**?
- ☑ List of **Parkinson's symptoms** you are experiencing: Which are new? Which are most troublesome?
- ☑ **Movement symptoms** (walking, getting out of chair, moving in bed, etc.)
- ☑ **Fluctuations** in your symptoms (typically correlated with medication cycle, eating, sleeping, and exercise)
- ☑ **Dyskinesias** (involuntary movements caused by Parkinson's medications)
- ☑ **Non-movement symptoms** (swallowing, speech, nausea, constipation, urinary frequency and/or urgency, drooling, excessive sweating, dizziness upon standing, swollen ankles, sleep disorders, restless legs, and more.
- ☑ **Changes in mental status** (depression, anxiety, cognition, ability to make plans, hallucinations, compulsive or excessive behaviors such as shopping, gambling, or sex)
- ☑ List **three items** that you most want to discuss with the neurologist. (There may not be time to address everything during your appointment, so it is important to **prioritize** your needs.)

Go!

- ☑ **Arrive early** to allow time for parking, using the restroom, getting to the appropriate reception desk, checking in, and filling out paperwork.
- ☑ **Bring along** water, a snack, and any medications you might need in case your appointment is delayed.
- ☑ **Ask a family member or friend** to accompany you to take notes, and remind you of anything important that has not been discussed.

At your neurology appointment:

- ☑ You did your homework, so you are prepared when your neurologist asks about your **symptoms and medications**!
- ☑ **Special requests:** Ask early in the appointment about prescription refills, disability forms, handicapped parking permits, etc. Often a nurse or secretary is available to work on these during your appointment.
- ☑ Address those **three major concerns** on your list of priorities.
- ☑ Ask for a referral to a **physical therapist** for help with balance, gait, strength, pain, and flexibility issues.
- ☑ Ask for a referral to an **occupational therapist** for help with handwriting, home modifications, driver evaluations, computer modifications, and adaptations to make dressing, grooming, cooking, and eating easier.
- ☑ Ask for a referral to a **speech language pathologist** for help with speech and communication problems (including vocal volume, clarity of speech, and increasing facial expressivity) and swallowing.
- ☑ Ask for recommendations regarding **exercise and nutrition**.
- ☑ Ask about participation in **clinical research trials**.
- ☑ Ask the **best way to get in touch** with the neurologist in between appointments: contact with nurse or secretary, by phone or email?

For **more information** about Parkinson's disease, contact the Greater St. Louis APDA Information & Referral Center at 314-362-3299 or visit our website at **www.stlapda.org**. ■

OPTIMISM

continued from previous page

Everyone Wins

As an Optimism event organizer, you are touching the lives of many from those diagnosed with Parkinson's disease to their families and loved ones. You are their support system, and we are yours. You can have a fun and fulfilling experience, donors can support an organization they believe in, and the APDA receives additional money for research, education, and support services.

If you need assistance planning your event, please feel free to contact the Greater St. Louis APDA at 314-362-3299. Remember that any amount of money—$20 to $5,000—is important to fight Parkinson's disease. ■

TAI CHI IMPROVES BALANCE IN PEOPLE WITH PARKINSON'S DISEASE

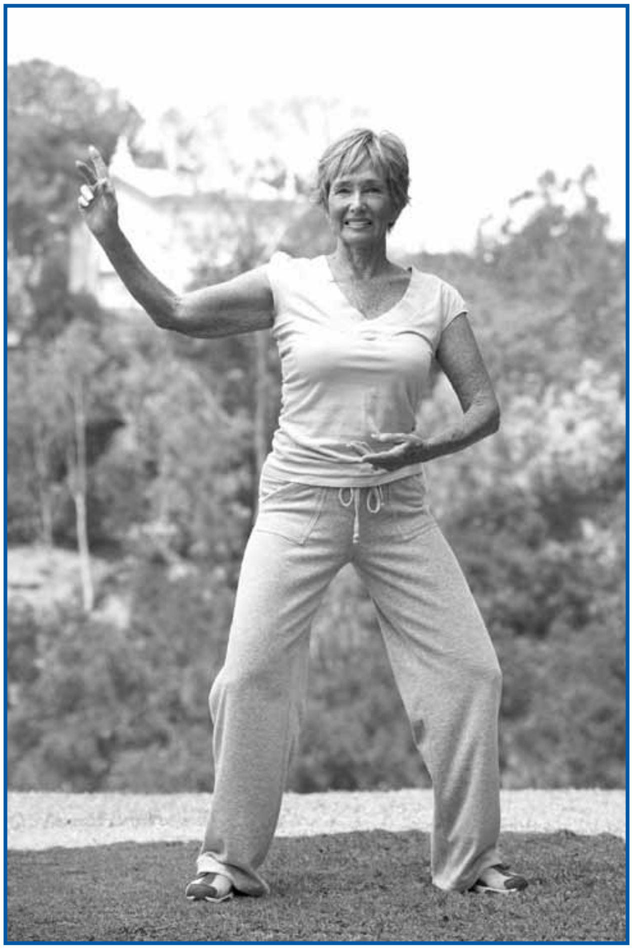
Tai Chi is a system of slow meditative physical exercises that emphasize gentle movements designed for relaxation, balance, posture, and health. It combines mental concentration, slow breathing, and dance-like movements.

Tai Chi may improve balance and reduce falls in people with Parkinson's disease (PD), according to research published in the February 9 issue of *The New England Journal of Medicine*. In Tai Chi, participants perform postures that flow from one to the next in a slow, graceful manner. Fuzhong Li, Ph.D., and his colleagues at the Oregon Research Institute in Eugene, OR, questioned whether Tai Chi might also improve postural stability—the ability to maintain balance while standing—in people with Parkinson's.

They randomly assigned 195 people with mild-to-moderate Parkinson's to one of three groups: Tai Chi, resistance training, or stretching. Each group attended a 60-minute class twice weekly for 24 weeks. Researchers assessed each person's improvement in tests of postural stability and other characteristics, such as gait, strength, and number of falls.

Results

- The Tai Chi group outperformed the other groups in two key indicators of postural stability: maximum excursion (how far a participant could lean in each of eight directions without falling) and directional control (how efficiently they could move toward a target).
- The Tai Chi group performed better than the stretching group in activities such as gait, strength, and a timed up-and-go test (how fast a person could rise from a chair, walk 10 feet, return, and sit down).
- Although similar to the resistance-training group, according to many of the measures, the Tai Chi group performed better than the resistance-training group in two categories: stride length and functional reach (that is, how far a person could reach forward beyond arm's length while standing at a fixed position).
- Participants in the Tai Chi group had fewer falls than those in the stretching group.



What Does It Mean?

This study demonstrates that Tai Chi may be more effective than stretching or resistance-training programs in improving postural stability and other activities of daily living in people with mild-to-moderate Parkinson's. These improvements could enhance a person's ability to perform activities such as reaching for objects in a cabinet, and also could reduce the chances of falling.

The researchers suggest that Tai Chi may improve postural stability by increasing the ability of subjects to sway at the ankle or hip to correct imbalances, or by improving their control of movement as they approach their limit of stability.

Christopher Goetz, M.D. noted, "Trainers must be vigilant to the postural and balance challenges that people with Parkinson's endure so that the exercises and maneuvers that are part of the program must be carefully individualized to the patient." ■

This article was originally published in the Spring 2012 edition of the Parkinson's Disease Foundation (PDF) quarterly newsletter, News & Review. *It is reprinted, in its entirety, with permission from PDF.*

Missouri Support Group Calendar

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
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**	**May 21**	**6:00 PM**	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
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	For Caregivers Only Shaare Emeth 11645 Ladue Rd., Library Conf. Rm.	2nd Monday	11:00 AM	Dee Jay Hubbard, PhD	314-362-3299
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	Linda Pevnick, MSW, LCSW, BCD Rich Hofmann	314-362-3299 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
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

continued on next page

Planned Giving

continued from previous page

- Specific Asset Bequest: “I give the Greater St. Louis APDA my car and Van Gogh painting.”
- Specific Amount: “I give $10,000 to the Greater St. Louis APDA to be used for research.”
- Bequest of a Percent of Residual estate: “I give the Greater St. Louis APDA 50% of the residue of my estate.”

There are many benefits to planned giving aside from helping a worthwhile charitable organization. You can retain ownership and use of the property during your lifetime, and your estate gets a charitable tax deduction. The amount given to charity is not subject to Federal estate tax.

We will discuss the other types of planned giving in future newsletter articles. We can help you through this process and answer your questions or concerns. Please contact the Greater St. Louis APDA for more information on Planned Giving at 314-362-3299. ■

MISSOURI SUPPORT GROUP CALENDAR

continued from previous page

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
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
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
St. Louis	St. Louis	Pre/Post-DBS Sunrise on Clayton Senior Living 7920 Clayton Rd.	3rd Thursday	1:00 PM	Steve Balven Stan & Donna Wilensky	314-249-8812 314-997-5114
Washington	**Franklin**	**5551 Weber Road**	**2nd Monday**	**6:30 PM**	**Carol Weber**	**314-713-4820**
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036

ILLINOIS SUPPORT GROUP CALENDAR

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
Carmi	White	Phoenix Rehab. & Nursing 615 West Webb St.	4th Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
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 & 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. www.parkinsonssupportcentralill.org	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

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.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Aerobics Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
Clayton	St. Louis	Tango Dance Class* The Center of Clayton 50 Gay Avenue	Wednesday	3:00 PM	Gammon Earhart, PhD, PT	314-286-1425
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	2:30 PM	Cathy Clough, MHA, COTA	636-537-3333 ext. 204
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	**Thursday** **April 5– June 14**	2:00 PM	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 Ste. 117	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.	**Thursday** **April 5– June 7**	2:00 PM	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

*** MUST CALL TO ENROLL**

Fox Trial Finder is LIVE!

When you participate in research, you give something money can't buy. Fox Trial Finder (https://foxtrialfinder.michaeljfox.org) opens the door to your opportunity to make a priceless contribution in the search for a cure. Parkinson's patients and their loved ones are eager to play an active role in finding the cure, and dozens of new clinical trials are launched each year. Yet challenges identifying participants too often mean that these studies finish late — or never really get started.

Today, 80 percent of trials fail to recruit enough volunteers within planned timelines. This slows research progress and deters funders from investing in Parkinson's research. It is estimated that only 1 in 10 people with Parkinson's participates in clinical trials. Yet in spite of the challenges, we know that this low participation rate belies the Parkinson's community's significant interest in stepping up to participate.

Fox Trial Finder makes it easy for patients and their loved ones to find personalized potential trial matches based on specific individual criteria (i.e., location and medical history). You can connect with trial teams to learn more about participating and stay alerted to future potential matches that arise as new trials start recruiting.

Our goal is to end 2012 with 10,000 registered volunteers willing to participate in research. To get there, we must continue to spread the word about this need – and opportunity – for the PD community. Join the effort to speed breakthroughs today by visiting Fox Trial Finder and creating your profile. The power of Fox Trial Finder grows with every new profile completed; so share Fox Trial Finder with family, friends, and members of your community. Thank you for being part of the answer. ■

REGISTER TODAY AND BE PART OF THE ANSWER TO PARKINSON'S DISEASE

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 birthday of Chuck Adams
Roselynn Gad

Kevin Blinder
Sid & Frances Axelbaum

The 90th birthday of Beverly Brick
Harvey & Lee Shapiro

The 90th birthday of Jack Chaiklin
Roberta Hayman

The DBS Team
Mark & Nancy Kodner

The 90th birthday of Ruth Dicks
Phillip & Susan Schreiber

The retirement of Joel Gerstel
Debbie Guyer

The 65th birthday of Mark Goldstein
Barbara & Mark Rosen
Grace & Harold Sarner

Sharon Kuhr
Larry & Andi Goldsticker

The 70th birthday of George Marble
Nancy, Tami, the O'Tooles, & the Walters
Robert & Karen Olsen
Karen Suroff

The 50th Anniversary of Mr. and Mrs. Sandford Miller
Mrs. Rita Rennard

The speedy recovery of Annalee Nissenholtz
Larry & Gail Hartstein

Bill Peacock
Mt. Vernon Business Women's Club

The research of Dr. Joel Perlmutter
Southern Illinois Parkinson Support Group

With gratitude for Dr. Perlmutter's wonderful PEP presentation in April
Debbie Guyer

The recovery of Mr. Leslie Rich
Penny Kodner

Martin A. Rudloff
Tina A. Rudloff
St. Louis Esprit Softball

The 90th birthday of Mrs. Harold Sachs
Ralph Goldsticker

The birthday of Sylvan Sandler
Gertrude Hulbert

Mike Scheller, PTA
Bill & Jan Erdman

The 1st birthdays of Abby and Lily Schreiber
Jack Strosnider

David Smith
Jane Smith

The recovery of Mr. Walter Stern
Penny Kodner

The 87th birthday of Jack Strosnider
Debbie & Karl Guyer
Parkinson's South County Monday Exercise Group

Jack Strosnider
Nelda Carlisle-Gray
Roland & Barb Lindhorst

Daniel and Carola Von Berg
John & Ramona Von Berg

The speedy recovery of Stan Wilensky
Debbie & Karl Guyer

REMEMBERING

Arnold Amann
I.A.T.S.E. Local 6
William & Gloria Zimmers

Jim Arnold
Cindy & Chuck Springli
Bette Thies

Jessie L. Bazzarone
Bill & Gwen Berutti
Dora Berutti
Brenda Brown
Jim & Mary Lee Brown
Mr. & Mrs. Ross J. Cascio
Mr. & Mrs. Victor G. Cascio
Bill, Andrea, & Pete Duncan
Robert & Denise Graham
Ken & Jackie Klaus
Jack & Stephanie Kochinski
Julia Kravanya
Mary & David Kurtenbach
Marsha Mussatto & Vi Edwards
Karen & Tom Tallman
Terry & Toni Wargo
Jim & Michele Wilson
Marion & Sharon Woodyard

Lawrence Birke
Carol Biermann
August & Annelie Birke
Charles Birke
Jeff & Robin Birke
The Leo Birke Family
Shirley Birke
Anthony & Zita Cafazza
Lora Sue Cisel
Julie & Drew Dubray
Judy Dunn
Dale & Diane Elfrink
Patricia Forget
Roberta Gittemeier
The Golfers & Gin Group
Danna Hardt
Tracy & Cliff Heitmann
Pete Hietpas
Jeffrey & Kathy Housman
Harry & Catherine Klein
Cheryl & Phil McKernan
John & Karen Meara
Nurses & Company, Inc.
Dennis Pohlmann
Don & Lucille Pohlmann
Kenneth Pohlmann
Rowdy Reds
Harvey Rogge
Laurentine Schmidt
Mr. & Mrs. Tim Shook
Tuesday Morning Exercise Group
Casimir Vrasic
Gene & Geri Wilmes
Linda & Terry Wilson

Marvin Blum
Randee Fendelman
Bill & Terri Taylor

Elva Bottchen
Penny Kodner

Shirley Bren
Janet Forsman

Robert Bubla
Ruth Bubla

Francis Charles Carpenter
George & Theresa Biber
Beth Connelly & Family
Liz & Gene Kuhn
Thomas & Mary Kuhn
JoAnn Maloy
Betty Mansille
Paul Matsuoka
Thomas McLaury
Christine Miller
Lorraine O'Brien
Joseph & Rosalie Pisciotta
Raymond & Luella Rew
Beverly Skolaut

Agnes Arlene Cates
George, Alice, Mike, & Heather Adams
Marjorie & Herschel Beane
Adron & Carolyn Cook
Carol Elliott
John & Judy Hartleroad, Jr.
Terri Hilgendorf
Duane & Candaice Kinder
Kris Reed
Robert & Ferne Ridenour
Rick & Jean Shimunek
Dorothy Talley
Doris Thompson

Mary Ann Cheney
Jacoby Arts Center

Marilyn Conway
Mary Lou & Aaron Fulton

Jack Craig
Jim & Jeanette Kille
Jonathan Krone
Dorothy Wood

Mollie Cregar
Debbie & Sid Boyer

Lillian Dalin
Barbara & David Furman
Karl & Debbie Guyer

LaVerne Delano
Jessica Duran

Helen Dickmeyer
Linda Delk

Jerry Diebner
Stan & Angie Klearman

Albeno Dori
Jovita Ann Johns
Pearl Mueth
Sandy Steppig

Dick Fagin
Jerry & Linda Kraus
Judy & Jerry Zafft

Damiano Falcone
Joseph & Alison Falcone

Bernard Frank
Charles C. Allen, Jr.
Craig & Jody Altman
Paul Arenberg
Art & Science Group
Richard Aselage
Bernadine & Paul Birenbaum
Suzie & Alan Broddon
Edie & Harvey Brown
Harvey & Karen Carafiol
Robert Carafiol
Arita & Ed Cleary
Sandy Coblitz
Sheila Cohen
Stanley & Anita Cohen
Mr. & Mrs. Charles Cook
Christine Cool
Steve & Marilyn Dardick
Ed & Diane Deutch
Jack & Ellen Deutsch
Ralph & Eilah Jane Edwards
Sandra Esrock
William & Laurie Falk
Bob & Lois Friedman
Sally & Don Friedman
Leonard & Roslyn Glaser
Jane Goldberg
Martin & Cookie Goldberg
Marilyn & Arnold Goldman
Deborah & Phillip Gould
Margo Green
Arthur Guller
Debbie Guyer
Ronald & Anne Henges
Ralph Herzmark
Charlotte & Alfred Hortmann
Terri Hosto
Fruma Kane
Jerry & Joan Kaskowitz
Toby Katz
Susan Kelter & Matt Hanewinkel
Robert & Susan Levin
Esther Levine
Dr. & Mrs. John A. Lewington
Lewis, Rice, & Fingersh
Joan Loewenstein & Norman Goldman
Robert Loewenstein
Laura Lueken
Gary & Shirley Madden
Joe Marchbein
Art & Joyce Margulis
Justus & Barbara Matthews
Kimball & Lisa McMullin
Missouri Cure's Staff
Barbara & Mike Newmark
Mr. & Mrs. Aaron Osherow
Jeffrey & Judy Pass
Amy & Larry Perlmutter
Art & Fran Poger
Steven Poindexter
Rochelle Popkin
John Pruellage
Jake & Leslie Reby
John & Maureen Riffle
Albert Rose
Ruth Rosen
Andrew & Ivette Rothschild
Phyllis & Marvin Sandweiss
Joyce & Richard Sass
Jackie Schiffer
Leanne & Harvey Schneider
Mr. & Mrs. James E. Schneithorst
Suzy Seldin
Babs Shapiro
Marcia & Bob Shapiro
Gretchen Smith
Ruth Sobel
Jean Srenco
Evelyn Tischler
Richard B. Walsh, Jr.
Washington University CRNA's

continued on next page

TRIBUTES & DONATIONS

continued from previous page

Wedgewood Partners, Inc.
Robert & Lynda Wiens
Stan & Donna Wilensky
Jerrold & Deborah Willis
Judy & Jerry Zafft
Stan, Sally, & Marci Zimmerman

Bruce Frushour
Terri Hosto
George & Nancy Marble
Joe & Donna Marshall

Janet Geno
Rolla Geno

Theresa Gibbar
Ralph & Kathryn Bruns
Marcelline Dairaghi
Andrew & Stacey Lammers
Guy & Kathleen McDonald
Harley & Liz Reynolds
Katherine Sapp
Robert & Patricia Schwendemann
Doris White

Kay Glassman
David & Mary Ann Gelfand

Frances Glazer
Ann Fingerhood & Family
Dr. & Mrs. Harry Glassman
Manuel & Edna Glazer
Don, Elaine, & Mandy Moore
Mildred Poletsky
James Sevem

Helen Goldsticker
Morton & Norma Baron
Alex & Cynthia Berger III
Toni Breihan
The Cohen Family
Margie Cornbleet
Madeleine Elkins & Harvey Wallace
Fred & Marilyn Firestone
Ann Fisher
Semon Frelich
Rick & Lisa Gans
Bob & Jeanne Golden
Larry & Andi Goldsticker
Debbie & Karl Guyer
Ralph Herzmark
Dr. John Holtzman
Bruce & Mary Horwitz
Julie & Warren Hutton
Dr. Arnold Jacobson
Joni & Bob Kaiser
Ruth Kessler
Michael & Ivy Klein
Eliot Kleinberg
Robert S. Klostermeier
June Laba
Linda Laramie & Philip Scharf
Barbara Levin & Steve Muchnick
Norman & Vicki Litz
Les Loewe & Jean Agatstein
Joe Marchbein
Al & Joy Melman
Jean Metzger
Tim & Nancy Persons
Jeanne Rimmel
Dee Rosenthal
Karen Schechter
Eleanor Schlafly
Ben Schulein
Ann Schweig
Bert & Elizabeth Schweizer, II
Harry & Reva Shank
Harvey & Lee Shapiro
Sher & Shabsin, P.C.
Denise & Rey Silver
Donald & Ruth Solomon
Jeff & Barb Smith & Family
The Craig Stern Family
Bert & Margie Talcoff
Dolores Toder
Mr. & Mrs. Simon Toder & Family
Jerry Ude
Randy & Ruth Wall
Robert & Lynda Wiens
Stan & Donna Wilensky
Richard Wolfheim
Richard Yalem

Colleen Goodridge
Bank of Old Monroe

Dr. Fred B. Goodwin
Charles E. & Mary E. Sharp

Hazel Bernice Gourley
Grace Sullivan

Thomas Grissom
Deborah & Kurt Hollman

Harold F. Grotefendt
Carl Conrad
Dorothy Conrad
Marg Hess
Jim & Ruth Ann Wheeler

Edward L. Hake
Julia & Charles Hake

Steve Heady
Ruth Zerface

Otto Hoelscher
Albert & Bernice Brockmeyer
Jim Brockmeyer

Dixie L. Holland
William & Sue Christie

Philip Johler
Ken & Susan Epstein

David Kennedy
Bill & Carol Allen
Carole Anne Baker
Norman & Barbara Bauer
Susan Belcher
Paul & Jane Bohannon
Phil Boston
Terry & Nancy Brown
Treg & Karla Brown
Kay Bruchhauser
Ben Burnley
Jim & Mary Cromeenes
Joan Dallas
Carl & Ruth Davidson
Rick & Wanda Dillow
Elaine Dunn
Dycus, Bradley & Draves, P.C.
Mike & Becky Estel
Michael & Debbie Fitzgerald
Robert Fowler
Kenneth & Irma Frick
The Goddard Family
Skip & Gail Hill
Barry & Teresa Holcomb
Jim, Wanda & Kim Honey
Margaret Jordan
Alice Kerns & Family
Richard & Nancy Kirschner
Dan Lewis
Brock & Gala Lockwood
Tal & Fay Lockwood
Cliff & Mary McMahan
Sharon Mullins
John Roseberry
Richard & Mary Ann Stout
SWCA Environmental Consultants
Marie & Robert Taylor
John & Liselotte Wells
Bob & Jean Wise

Elmer Kleeschulte
Patricia & Brian Bax
Joan Busby
Roland & Arleen Fisher
Pat Griesenauer Lewis
Barb & Art Pondel
Rosie Prinster
Jeanette Vogt

Robert Klefisch
Richard Klefisch

Ray Knierim
Jack Strosnider

Albert Kopolow
Alan & Peggy Schaffer

Lester Kroeger
Thomas & Madonna Marnati
Florence Peck
James Peck Family

Edgar Henry Kummer
Wallyball/Bunco Gals

James LaPorta, Jr.
Fred & Frankie Appleby
Jeannie Boettcher
Larry & Linda Boleach
Brown Shoe Company
Ruth & Gunnar Brown
Helen Douglas-Taylor
Gary & Jean Eversmeyer
Mark Forbes
Rebecca Geraty
Hazelwood West Math Dept.
David & Libby Hosler
John & Mary Ellen Keaveny
Kyle & Alisha Kudron
Dr. & Mrs. Guido A. LaPorta & Family
Douglas & Shannon Owenby
Dominc & Sharon Thompson & Family
Robert & Debra Trost
Jason & Sara Wiegman
Jerry & Sabra Wood

Joan Longo
John & Beth Morris
Elisa & Andrew Robinson

Nick Ludwig
Diane Ludwig

Jacob Manuele
Anthony & Rhonda Aiello
Joseph Aiello
Katherine Aiello
Jerry Amaro
Anthony & Zita Cafazza
Vinie & Diane Castelon
Shirley & Bernard Corno
Elaine Edwards
Kathleen Edwards
The Huffmon Family
Robert & Karen Lewis
Michael Lodes
Anthony Manuele & Katharine Starkey
Anthony & Magdalene Manuele
Joe Manuele & Nancy Henrichs
Margaret Manuele
Roy & Marlene May
Mike & Marty Meier
Steven & Lynn Moro
William & Christine Peterson
Steve & Sue Shumate
Fran Smith
Eugene & Catherine Terbrock
Dennis & Janice Thousand
Rose Marie Vaccaro

Eugene McDowell
Larry & Lola Laurent
Stephen & Sarah Johnson
David & Christine Sadler
Jean & Jerry Sadler
Charles & Sandra Smith

Ora Fay McGinnis
Loretta Pittaluga

Gina McGoldrick
Lauren Krimsky

William Meyer
Terri Seger
Sharron Montoya
Julia Davis

Christian Nordstrom
Heather Wood

Ira S. Oglesby Sr.
Allan & Alice Mollett

Jake Pantukhoff
Donald & Barbara Correll

Mary Paz
Allen & Arline Kolons

Susan Piazza
Deanna Siller Duda
Carmen M. Marty
Carolyn Q. Parker
Laura B. Wilhelm

Herb Pitts
Jerry & Kathryn Stroder
James & Debra Twellman

Melba Poole
Grace Barbee
Kevin & Sarah Hancock
Timothy & Sheryn Just
Debra McCallister
Lois McLain & Rita Potter

Donald Rasche
Kay & Dave Wasmuth

Merle Rockwell
Sally Boughman
Mr. & Mrs. Allen Burns
Kenneth & Dianne Ehle
Joseph & Theresa Gordon
Ron & Flora Hogue
Knights of Columbus, Christ Prince of Peace Council 12986
Robert & Lucila McMillion
Catherine Rockwell
Mr. & Mrs. J. Stubblefield
Bob & Joan Weissert

Joseph Rothberg
Joanie & Mark Goldstein

Ed Scallet
Lee & Harvey Shapiro

Vernon Schmidt
Grace Sullivan

Jimmy Shaner
Bud & Phyllis Ross

Ronald Simon
David & Lora Biernbaum
Randee Fendelman
Larry & Gail Hartstein
J.H. Berra Construction
Phil & Ilene Kaiser
Kiefer Bonfanit & Co.
Richard & Ruth Just
Erica & Mitch Lefkowitz
Mary & Art Lottes
Mainini Tile Co.
Gene & Lisa Mainini
Joe Marchbein
McKelvey Homes & James G. Brennan
Meadowbrook Country Club
Bobbi Nathan
Ava & Steve Schwedt
Emily & Todd Schwedt
The Sterling Company
Bill & Terri Taylor

Billy Smith
Debbie Guyer
House & Associates LLC
W. Wiley McFarland
Robert E. Miles
Phil & Sandy Panagos
Linda S. Rieves
Carl & Thelma Stone
Bette Thies

Enid Spilman's mother
Margie Smith

Ann Spolter
Larry & Andi Goldsticker

Edwin Louis Stamm II
Barbara Atteln
Ruth Ann Hager
Mike Hinkle

continued on next page

TRIBUTES & DONATIONS

continued from previous page

Arline Kretschman
Beverly Favazza
Karen & Bob Goode
Michael & Gloria McBride
Lee Metcalf
Ilene Murray
Audrey Naumann
Anita Selley

Richard Stang
Barbara Finan
Sheila & David Shortt

John Steinmetz
Joe & Margaret Adams
Betty Benson
Brian & Susan Caimi
Mary Factor
Warren & Joyce Feeler
Vicki & Taff Harris
Chuck & Ruth Huntbach
Michael & Pamela Kelley
Jim & Marilyn Lawless
Kelly LeStarge
Rene Lusser
Robert & Bonnie Mathews
Marty Roberts
Dennis & Colleen Woerheide

Charles Stephens
Elaine Hall
Jose & Harriett Orozco
Marge & Jerry Right
Solid Fifty Club
South County Business Group
Richard & Stacy Stephens

Lorraine B. Suntinger
James & Susan Fritz

Margaret Tretter
Vicki & Gary Anderson
Del Gross
Brenda Halastanis
Al & Jan Keller

Dr. Herman Turner
Jeff Sandler

Lorena A. Walker
Dewayne Hamner
Wendy & Randy Smith

Sam Weber
Harlan & Barbara Floom
Roberta Hayman

Dr. Allison Willis's Father
Debbie Guyer

Elizabeth Wright
Bethesda Health Group
Robert & Carolyn Harmon
Helen Meyer
Jeanne & Jim Nowicke
Melissa Shepard
Joseph & Susan Sivewright
Joyce & Richard Snyder
Marilyn & Hardy Sumner
G. David Voges
Mark & Mary Ellen Voss

GENERAL

Nancy & William Anderson
Dennis & Kay Anstine
Thomas & Charlotte Benton
Bill & Ada Billings
Janina Buenrostro
Orville & Virginia Burkemper
Robert R. Butenschoen
Patricia Carter
Mary Cayse
Dick & Nancy Chin
Roy Kenneth Conner
Terry Conner
Bill Cottrell
Bob & Linda Coulter
Francis & Bamby Craig
Barbara Crow
Jim & Doris DeLaet
Lucy Ellen Donaldson
Diane & Don Donlon
Larry Dreppard
Charlotte Eldredge
Janet Rice Forsman
James & Paula Frick
Dorothy Gacioch
Jackie Garver
Don & Carol Giger
Ranjita Gosain
Clayton Goss
Harry Grannemann
Hord Hardin, II
Irene Hart
Bernhard & Else Hartmann
Dan & Regina Hendrickson
Ray & Muriel Hoffstetter
Don Hoit
William & Margaret Jamison
Ryan & Carol Jones
Raymond & Ruth Keating
Kay Keilholtz
Karen Keth
David & Marilyn Klasing
Ladue Chapel Women's Association
David Michael Lansdown
Linda Laramie & Philip Scharf
Jerome & Elizabeth Lester
Ann Lux
Christel Maassen
Dr. & Mrs. Brad Marrs
Richard & Sharon Marsh
Charles & Sandra Martin
Helen Martin estate
Char Ann Meloney
Janet Meyer
James & Pamela Miller
Floyd & Diana Morgan
John & Beverly Paquet
Jim & Jean Peterson
Karen Pfitzinger & John Kehoe
Margie Reimer
Nora Sanders
Donna & Donald Sartor
Rozanne Schaefer & Lawan Horsley
Scottrade Employees
Martin Shrader
Charles Siebert
Beatrice & Marvin Siegfried
Larry & Jacqueline Simon
David & Cindy Smalley
Keith Smith
Milton & Carol Stohs
Jack Strosnider
William & Marilyn Strothman
Sara Jane Weinhaus
Jean & Bob Wunderlich

YOU MAKE THE CALL

Dave Myers

In the months since being diagnosed with Parkinson's disease, I've bumped into many old friends who are quick to apologize because they didn't call me after hearing about my new challenge. "*I should have called*…but I didn't know what to say" is an all too common refrain. The phrase, "I didn't know what to say," should be eliminated from everyone's vocabulary. You've known me for 5, 10, 15, 20 years; you're a smart person; you have a myriad of communication options; you must sense that I am, if not suffering physically, certainly experiencing some emotional pain, and you *don't know what to say?* You need new vocal cords and some guts.

A bit harsh, I admit, but think how selfish those words sound. It might make *you* uncomfortable to make that call, so your potential discomfort overrides the comfort you might provide someone who is facing perhaps the biggest challenge in his/her life? In your world, avoiding a little awkwardness takes precedence over showing you care?

So, the next time you think, "I should call, but I don't know what to say," get a mirror and have a talk with the person staring back at you. And think about your first thought. When you get to "I should have called, but..." *stop*. Your initial instinct is right on. Of course, you should call! And know this: If you call and babble, stammer, and generally butcher everything your English teachers ever taught you, I'll only remember that you called. If you call and say something totally stupid, I will remember that you called. If you call and find it hard to go on, I'll only remember that you called. At a time when I am just plain scared of my own mortality and feeling things I've never felt before, I don't care *what* you say or *how* you say it.

By saying nothing, you're saying a lot. The silence is deafening…and revealing. Not knowing what to say or saying it using something less than the King's English is pardonable. Not caring enough to place the call is selfish, gutless, and inexcusable. My response to "I should have called, but I didn't know what to say" goes like this: "You didn't call and I know *exactly* what to say." *Make that call!* In the wise words of the Wizard of Oz …have a heart, use your brain, and muster up some courage.

As I write, I temper the emotion I feel for this topic. I recognize that not everyone has the ability to say exactly the right thing at exactly the right time…especially to a friend in a tough spot. Conversely, a friend in a tough spot is a friend first and foremost, not a grammarian. He/she values your friendship, not your use of syntax. In my career and in my life, I use an adage that seems to work remarkably well in a variety of situations. When all else fails, tell the truth. Role play with me— YOU: "Hey, I don't know what to say." ME: "You don't have to say anything. The fact that you called speaks volumes."

There, was that so hard? ■

Reprinted with permission from the author and Parkinson News, *Volume 32, Issue 2, February 2012.*

TRAVELING WITH PARKINSON'S DISEASE

By Alison Monette, RN, BSN, Deep Brain Stimulator Program Coordinator, Central DuPage Hospital

Someone once said, "Never traveling is like reading the same chapter of a book over and over again." Receiving a diagnosis of Parkinson's disease does not mean the end of traveling, whether to new places around the world or back to the places you know and love.

Research Your Trip

The most critical task when planning to get away is researching your destination. Gone are the days of spontaneous travel. You need to know where you are going, who you are going with, and what kind of resources will be available to you once you get there. This is important, even if you are traveling back to a familiar place. It is important to look at places you have been with a new set of eyes, taking into consideration your diagnosis and the restrictions associated with it. The more you research, the more prepared you will be. Do not assume you will find your way around once you reach your destination.

Consider all of your options carefully, especially lodging. Look for places that have an elevator or ask for rooms on the ground floor if navigating stairs are difficult for you. Ask if handicap accessible rooms are available since they tend to be closer to the entrance, roomier, and fitted with assistive devices to make mobility easier. Take advantage of what is available. For example, when choosing between resorts on a Caribbean island, look for the facility that provides golf carts to drive between your room and the beach or restaurants if walking long distances is difficult for you.

Once you have decided where you are going to stay, educate yourself about the location of the nearest hospital and pharmacy. If you are traveling outside of the country, make sure you know the limitations of the local healthcare system and what your health insurance plan will and will not cover. You may also consider adjunct health insurance.

When it is time to decide who is going to go with you, consider your travel companion carefully. Decide if whoever goes with you needs to be aware of your diagnosis, needs, and limitations. If you are more advanced and need a greater level of care, think about if it would make sense for a caregiver to accompany you on your trip.

While your goal should be to engage in the things you enjoy, plan activities that match your physical ability. Safety should always be at the forefront of your mind when planning how you are going to spend your free time. For certain outdoor pursuits, consider discreetly informing a guide or activity leader of any concessions you may need.

Navigating the Airport

Allow yourself plenty of time to navigate your way through the airport. Airports tend to be crowded, fast paced, and stressful…three characteristics that may make Parkinson's symptoms increase. For example, gait freezing tends to get worse if you are rushing or in the midst of a crowd of people. Consider smaller airports if they are an option, and try to take non-stop flights so you do not have to make your way through multiple airports. Ask for assistive devices (wheelchair, cart) if you have to cover long distances between the parking lot and your gate. Use rolling luggage, and take advantage of curbside check-in if it is an option. Make sure you wear appropriate clothing and shoes, keeping in mind you may have to empty pockets and remove shoes to get through security. With Parkinson's, rushing may actually make you slower, so try to stay calm and focused. Ask if your neurologist would be willing to write you a letter stating your diagnosis to carry with you. That letter may inspire the staff at the airport to be more patient and allow you extra time to complete tasks.

Aisle seats on airplanes are preferable to window or middle seats because they allow more space to stretch your legs and prevent you from having to climb over another passenger to get to the bathroom. Ideally, a person with Parkinson's should not sit inactive for more than 20 to 30 minutes at a time, so move your legs and stretch regularly, get up, and walk when you can.

Medication Management

It is crucial to make sure you have enough medication with you to last for your entire time away from home, and it may be beneficial to bring extra medication with you. Plan ahead and request refills to be authorized by your physician if you do not have enough medication on hand. Medication is your lifeline when you have Parkinson's disease, so do your best to avoid having to stop anything abruptly. Pack your medications in their original bottles with up-to-date directions to avoid any confusion. If you use a pill box, bring it with you and separate medications into the pill boxes once you are settled. Don't forget to pack other accessories as well, such as a pill cutter or alarm if these are the things you are familiar with using at home. Outside of having the pill bottles, keep a current list of medications on your person at all times in case of emergency.

Many Parkinson's medications are taken several times daily and work best when a strict schedule is followed. Discuss with your neurologist how to adjust your timing of doses if you will be traveling across time zones on your vacation. The rule of thumb is this: Maintain the same number of hours between doses throughout the day based on the time zone you are in when you wake up in the morning. For example, if you take your medications every three hours and you wake up in Illinois but travel to California, continue taking your medication every three hours from your first dose in the morning until you fall asleep in California. When you wake up the

continued on next page

TRAVELING WITH PD

continued from previous page

next morning, you adjust to California time. The time interval between doses is more important than the actual time of day. Keep in mind that this may mean you will need to add a dose at the end of the day of traveling if it is a longer day than usual (make sure your neurologist is aware of additional doses).

Rest

Since you want to enjoy your travels to the fullest, don't overdo it! Give yourself time to acclimate to new surroundings, and schedule time for rest every day. If you know there are times during the day when you function better and have more symptom control, plan activities around your "on" time. Keep hydrated and remember to drink more if you are in the sun or more physically active than usual. Eat frequently. Remember: Any stressor like hunger, dehydration, or fatigue will make your Parkinson's symptoms worse.

Considerations for the DBS Patient

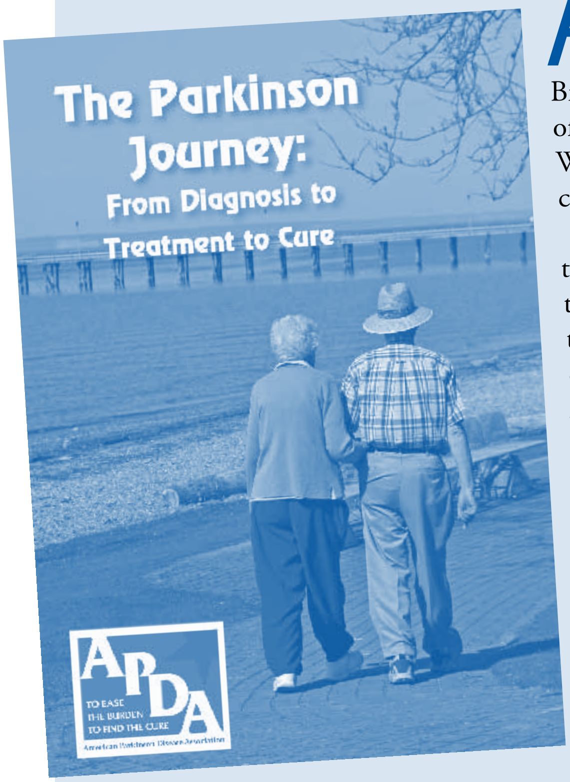
Always carry your Medtronic card with information about your device(s). Have it accessible when you are at the airport, and provide it to the staff at the security check point. You should be pulled aside and patted down instead of going through the metal detector. Make sure to pack your Access Review (patient remote) so you have the ability to check you stimulators and turn them on or off. DBS is performed in major cities world-wide, and you can always find the nearest provider by contacting the manufacturer, Medtronic. If you have to be hospitalized while away from home, make sure to communicate to hospital staff that you cannot have an MRI.

When Travel Is Not A Good Idea

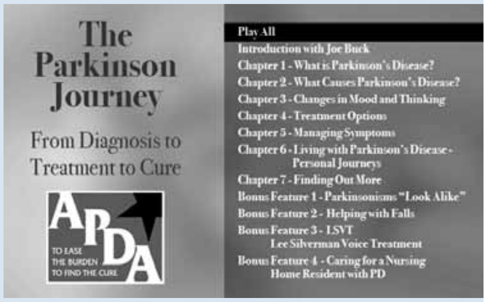
20-40% of people with Parkinson's have varying cognitive deficits, which may include forgetfulness and confusion. Some may also have hallucinations, often as a side effect of their medications. It is important to know that cognition and hallucinations may increase with changes in location and/or routine. Traveling is not contraindicated, but you should have a plan of action in place for mental status changes. Some ideas include bringing familiar items with you, bringing along someone you know well to help reorient you, and asking your physician to prescribe medication that you can take on an as needed basis for disorientation.

There is a class of Parkinson's medications called Dopamine Agonists that have the potential to cause compulsive side effects. Examples of dopamine agonists are Mirapex, Requip, and Neupro. Very few people who take these medications experience compulsive thoughts or behaviors, but if you do, you should be sure to discuss this with your neurologist. Never plan trips with the intention of satisfying compulsive urges.

So, with the right preparation and planning, you can lead an active, healthy life filled with travel and adventure, despite your diagnosis of Parkinson's disease. Bon Voyage! ■



After years of planning, grant writing, and raising funds, and months of writing scripts, filming interviews with physicians, patients, and caregivers, we are ready to release *The Parkinson Journey*. This DVD features Fox Sports Broadcaster Joe Buck, whose father Jack developed Parkinson's in the final years of his life. In addition, it includes leading Movement Disorders specialists from Washington University School of Medicine, therapists, members of our exercise classes, support groups, and individual patients and their caregivers.



These DVDs will be distributed throughout the state of Missouri to physicians, nursing facilities, therapists, libraries, social workers, patients, caregivers, and family members. They were made possible because of the efforts of the Fraternal Order of Eagles, who raised funds throughout the state of Missouri for one year, with the goal of educating those who deal with and experience Parkinson's disease (especially those living in rural communities) on the current treatment of this disease and resources.

We encourage you to contact the Greater St. Louis Chapter for further information, or to share the names and addresses of physicians who you see or nursing facilities where Parkinson patients reside who may wish to receive this DVD to learn more about the Parkinson Journey. CMEs for physicians will be provided through WUSM.

These may be ordered through our website at **www.stlapda.org**. ■

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

GOT MAIL?

Publishing and mailing these newsletters costs $1.00 per magazine.

If you no longer wish to receive this publication or other mail from the Greater St. Louis APDA, please email **drehere@neuro.wustl.edu** or call (314) 362-3299 and your name will be removed immediately.

To reduce our costs for newsletters returned with incorrect addresses, please inform us of any change in your address so that we can ensure you receive the newsletter.

SAVE THESE DATES!

Mon., May 21 **The 14th Annual Nat Dubman Memorial Golf Tournament with John 'Mo' Mozeliak, GM of the World Champion St. Louis Cardinals, as the Honorary Chair and Brook Dubman, Chairperson**

The golf tournament takes place at Lake Forest Country Club and includes 18 holes of golf with cart, course beverages, breakfast, lunch on the course, cocktail reception, appetizers, prime rib dinner buffet, award ceremony, auction, and Q & A with Mo. If golf is not your bag, join us after the round at 3:00 p.m. for open bar, appetizers, dinner buffet, Q & A with Mo and auction! See golf invitation on website www.stlapda.org or request an invitation for registration and entrance fees at 314-362-3299. Breakfast and registration start at 8:30 a.m. with a 10:00 a.m. Shotgun Start.

Tue., June 26 **PD Expert Briefing Webinar**

Check PDF website at www.pdf.org/parkinsononline or call 800-457-6676 for further information.
All sessions meet from 1:00-2:00 p.m. (eastern time).
Understanding the Progression of Parkinson's with Ronald E. Pfeiffer, MD.

Sat., July 14 ***Early Diagnosis and Signs of Parkinson's That Doctors Often Miss***

Dr. Michael Rezak, Medical Director of the APDA National Young-Onset Center, will speak at Congregation Shaare Emeth, 11645 Ladue Road. The program will start at 1:00 p.m. PEP flyer will be mailed in June.

For those of you who were unable to attend the Progress in Parkinson's disease research update held on April 1 with Dr. Joel Perlmutter, you may purchase a DVD of his presentation for $15 including shipping. The 450+ in attendance agreed that this was one of Dr. Perlmutter's finest programs.