

### 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."

## DREAM TEAM

Joel S. Perlmutter, M.D.

The team at the APDA Center for Advanced Research at Washington University continues to make substantial progress. This team is a combination of faculty, staff, funding from the Greater St. Louis Chapter of the APDA, and continued support from the National APDA.

We continue to make progress in understanding various aspects of deep brain stimulation (DBS). Our DBS team includes Drs. Tabbal, Hershey, Black, Karimi, Earhart, Foster, Campbell, Videen, Mink, Dowling and Rich; Marie McNeely (graduate student); and multiple staff including Johanna Hartlein, Dawn Lintzenich, Angie Wernle, Sandy Sagitto, Hugh Flores, Phil Lintzenich (unrelated to Dawn), Patrick Weaver, Susan Donovan, and others. This year much of our focus has been to try to determine the differences in the effects of stimulation of different parts of a small part of the brain called the subthalamic nucleus (STN). This is the target for most of the people with PD, and there has been some controversy about whether different parts of this small region of brain (not more than 1/4 - 1/3 of an inch from top to bottom) have different effects on movement, thinking, or mood. We have now published a study describing how a certain type of critical thinking may be more affected by stimulation of a lower part of this brain region. This study was just published in a prestigious journal, BRAIN, with Dr. Hershey as the lead author. Drs. Hershey and Black have obtained an additional National Institutes of Health (NIH) grant for this DBS research on mood and thinking. Interestingly, walking or movement may be affected nearly equally with stimulation throughout the extent of this brain region, and a paper describing these findings has been submitted by Marie McNeely. In addition, we are completing preparation of a manuscript describing the effects of DBS on mood and will be presenting findings of DBS on speech. As

for many of the studies that I will describe, they could not have been conducted without the chapter support which not only enabled us to initiate these studies but continues to help us



pursue new ideas and collect preliminary data. Collection of this preliminary data has resulted in the two NIH grants that currently fund the bulk of the studies.

Dr. Earhart and her graduate students (including Marie McNeely and Daniel Peterson) have continued investigations into the effects of various exercise programs and dance on walking and balance in people with PD. They continue to publish many research papers and have been the leaders in dance therapy for PD – an increasingly common form of therapy throughout this country and around the world. Dr. Earhart also has been actively studying turning problems in PD and how they relate to freezing (when the feet suddenly stop). The initial work in these areas has been supported by the chapter and now has support from an NIH grant. Dr. Pickett along with Dr. Earhart is beginning to study how various therapies affect brain networks important for walking and turning. This represents a new foray into MRI studies with several of us working in brain imaging. These are particularly interesting studies since they may reveal how therapy affects brain function, thereby providing an entirely new approach to optimizing such treatments. Stay tuned for more to come from these promising investigations.

Dr. Racette along with Drs. Criswell, Wright Willis, Evanoff and Checkoway continues to investigate environmental factors that may contribute to the development of parkinsonism. Dr. Wright Willis just published what I consider

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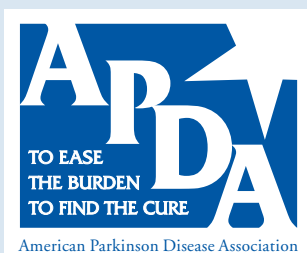
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### EDITOR

Deborah D. Guyer



# LETTER FROM THE PRESIDENT

Matt LaMartina

What can be more important than living life to the fullest? By supporting the Greater St. Louis Chapter of the American Parkinson Disease Association, you will help enhance the quality of life for people with Parkinson's disease, their families, and caregivers, along with funding critical Parkinson's research, that will, as we say, "Ease the Burden – Find a Cure."



More than 130,000 people will be newly diagnosed with Parkinson's disease in the United States this year alone. Your donation to the St. Louis APDA will allow us to sustain our existing programs, and support our efforts to develop and implement innovative new programs that respond to the changing needs of our Parkinson's community.

In addition to supporting local patient services, your gift touches the lives of people with Parkinson's globally by funding research and clinical trials, many of which are producing encouraging results. Dr. Perlmutter's article focuses on some of the research studies that have been funded in part by the St. Louis Chapter this past year. It is pretty impressive!

On behalf of individuals with Parkinson's disease, their families and care partners, and researchers, I would appreciate your joining me in making a contribution to the St. Louis APDA. Please return the enclosed tribute envelope or make a secure donation at our website [www.stlapda.org](http://www.stlapda.org) to make a gift that touches the lives of people impacted by this disease.

From all of us at the St. Louis APDA, I thank you in advance for your generosity in helping all members of the Parkinson's community. ■

## CARING FOR THE CAREGIVER

Our lives change – often in unexpected ways. Being a caregiver is not easy, and those who do it are special. The St. Louis APDA announces the formation of a special new support group, For Caregivers Only, facilitated by Dr. Dee Jay Hubbard. He brings a unique perspective to working with caregivers and families in that he has extensive background and experience with communication problems of individuals who have neurological disorders, and family counseling.

In addition to careers in Speech Pathology, Counseling, and Marriage Education, Dr. Hubbard founded the Life After Stroke group, an educational and support group for stroke survivors and caregivers, and also helped develop a peer counseling program for stroke survivors and caregivers that was adopted for use in several states. At present, he

facilitates caregiver groups at TRISL and BJC Extended Care Facility.

Because of his passion for caregivers and families, Dr. Hubbard has agreed to facilitate the St. Louis APDA's For Caregivers Only support group. Parkinson's disease doesn't just affect the patient; it impacts the entire family. If you have not attended and wish to receive meeting notices, please contact the I & R Center at 314-362-3299 or send an email to [guyerd@neuro.wustl.edu](mailto:guyerd@neuro.wustl.edu) and you will be added to the mailing list.

Dr. Hubbard plans to organize Train the Trainer sessions so caregiver support groups can continue in a variety of locations closer to your homes in 2011. If you or someone you know would be interested in leading one of our caregiver support groups, please let Debbie Guyer know of your interest. ■

# MISSION: POSSIBLE

Debbie Guyer, M.A.

In July, I answered an incoming call from a newly diagnosed patient who introduced himself and said that he was interested in learning about Parkinson's disease. As we chatted, I found out that he had heard about us through his church bulletin. Later that morning, Cherstin and I were discussing church bulletins as a great place for increasing awareness about various resources for their members. With 130,000 newly diagnosed cases of Parkinson's each year, we know that we are merely scratching the surface when it comes to making the connection with patients who have been diagnosed or families who are wondering what that diagnosis means for their loved ones. Do you remember what it felt like the day your doctor said those words, "You have Parkinson's disease."

Can you recall the many thoughts which ran through your mind...and that of your spouse, your children, and your employer?



It is our goal to establish optimal quality of life for our Parkinson's community through awareness, education, advocacy, and care. And it begins by making the connection across the states we serve. Access to information enables us to meet challenges we face in our lives head on. That is why the mission of the APDA is to ease the burden (create a resource to help people with Parkinson's and their families live their best possible

life today) and anticipate the cure tomorrow. Together we can make great strides in advancing this vital mission for all impacted by Parkinson's disease.

Help us reach those people who may feel alone and helpless, and not know where to turn upon receiving the news of this diagnosis. Talk to the people at your churches and synagogues about mentioning the resource of the St. Louis American Parkinson Disease Association in their bulletins – we are just a phone call away. Let your medical doctors know of the resources you have found to live the best possible life today. Don't let it be the best kept secret! There is so much to be learned – so much to share – but making that initial connection is the key, and you, our ambassadors, can make that happen. ■

## FAMILY TRIBUTES

At our recent fall fashion show, we introduced the Family Tribute Program. This program honors the life of a person and their family living with Parkinson's disease every day and who continue to do so with grace and style. Prior to the event, four families came together to make contributions to the St. Louis APDA in honor of their loved one with PD. A certificate was presented at the luncheon to this inaugural group of recipients and/or their family representatives. At the conclusion of the luncheon, another family and their friends attending the event contributed \$1,000 and so we gained a fifth Family Tribute honoree. We are proud to report that this special Family Tribute is just beginning and will continue. We hope that you and your families will join us in commemorating milestones and celebrations as we congratulate families participating in our inaugural recognition at this year's fashion show.

In order to qualify for a Family Tribute, a minimum of \$1,000 must be contributed collectively in honor of a person/family. These Family Tributes will be acknowledged in the newsletter and a certificate will be mailed to the recipient.

*Two inaugural Family Tributes in excess of \$5,000 were awarded to:*

**Kay and Bill Bruchhauser** in honor of their 50th wedding anniversary and on the occasion of reaching this very special milestone together.

**Walter Donius** from Bill and Connie Donius honoring their father and husband, with a generous family tribute. Other guests at the event, Liza Rael & Mark Lombardi and Jim & Kathy Lunan have also contributed to this tribute honoring Walter Donius.

*Those achieving over the \$1,000 level included:*

The Rakestraw family honoring their matriarch, **Betty Rakestraw** (wife, mother, grandmother) in cel-

ebration of her effort to fight this foe (PD) and in celebration of her life: Bud Rakestraw; Scott, Julie, Stephanie & Alex Rakestraw; Shari & Bill Reller; and Christine, Dave, Kendall & Jordan Sadler. Other guests contributing to the Rakestraw family tribute included Kelly Johnson, Sue Warden, and Mary Mercurio.

The Dalin family established a family tribute honoring **Lil Dalin** (Mom and "Maw Maw") on the occasion of her September birthday and in celebration of her wonderful life: Barbara, David, Mitch & Lisi Furman; Gary & Debbie Dalin; Rachel, Brandon, Malory & Blake Biederman; Gwen & David Tichauer; Stephanie & Rich Torres; Debbie, Karl & Brittany Guyer; Erin & Marc Schreiber; and Jeff, Debbie, Jamie, Zach & Andy Dalin.

Friends and family honoring **Dan Gibson**: Bob & Patty Rowland, Judy Kent, Paul & Lois Pfeiffer, Maureen Orbe, Roger & Haruko Bresnahan. ■

## DREAM TEAM

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to be the best study of the prevalence and incidence of PD in the U.S. Using national Medicare records, they have been able to determine how often different ethnic groups develop PD. It turns out that whites are twice as likely to develop PD as African-Americans. Asians have a prevalence closer to African-Americans whereas Hispanics are closer to whites. Further, they found that the risk of having PD is not evenly distributed across the U.S. but rather is more common in the Midwest and Northeast. This “splotchy” distribution suggests that local environmental factors may contribute to the development of PD. In fact, their latest studies provide evidence that living in areas with heavy metal exposure may be associated with a greater chance of developing parkinsonism. Dr. Racette’s team has also continued to investigate whether welding exposure increases PD risk. Their team travels to cities to examine union members exposed to welding and those not exposed to welding to determine if there is a difference in development of any clinical signs of parkinsonism. Drs. Criswell and Racette also bring some of these individuals back to Washington University to use PET and MR imaging to determine whether there have been any effects on the brain from such exposures. Results from some of these studies will soon be published. Again, much of this work including the initial studies and some of the imaging studies has been done with support from the chapter. Drs. Criswell and Wright Willis also obtained mentored career awards to help support this work. Dr. Racette also was awarded an NIH grant supporting a portion of this work.

We are now in the fifth year of our study funded by the St. Louis Chapter to investigate the relationship of dementia with PD and have made substantial progress again this year. People with PD are at increased risk for developing trouble with memory, concentration, and problem-solving. These diffi-

culties, called dementia, are symptoms commonly caused by Alzheimer’s disease. Up to this point, we believed that people with PD developed dementia for a couple of reasons. First, we thought that many developed Alzheimer’s disease in addition to PD. A second cause is a condition known as Lewy body disease in which a protein called alpha-synuclein abnormally clumps in brain cells or fibers. Since the only way to determine the exact cause of dementia in someone with PD is to examine the brain after death, we have been working on a series of tests including neuropsychological testing, MR scans, and a type of PET scan called PIB. PIB scans identify an abnormal protein in the brain called amyloid that occurs in people with Alzheimer’s disease. Thus, we thought that the PIB PET scans would help us determine whether an individual had Alzheimer’s as a cause of their thinking problems. This past year we published three papers describing some of our results (the last one just last week), so this is hot off the press! We have found that PIB scans do identify this abnormal protein in the brain in some people with PD, but more importantly we found that this does not necessarily indicate Alzheimer’s disease. In our study, people are followed up long term, and all have agreed to donate their brains upon death. This incredibly generous gift from some of our research participants is an important contribution. We found that those with abnormal PIB scans had excessive amyloid in the brain – like people with Alzheimer’s disease – but did not have other features in the brain necessary to confirm that diagnosis. In fact, all of these people with abnormal PIB scans also had Lewy body disease affecting much of the brain. So, we now believe that dementia in PD is caused by this Lewy body disease or Lewy body disease with abnormal amyloid and that Alzheimer’s disease may be a relatively uncommon cause of dementia in people with PD.

### SAVE THE DATE

**Nov. 21, 2:00 P.M.**

Parkinson Education Program  
with Dr. Joel Perlmutter  
Congregation Shaare Emeth  
11645 Ladue Road

Of course, these are just our initial findings and more research is needed to confirm this idea. However, this is extremely important as it will direct how and what therapies we test to treat thinking problems that may arise. Our team for these studies has expanded and now includes Meghan Campbell, Erin Foster, Michelle Burack, Nigel Cairns, Tamara Hershey, Johanna Hartlein, Joanne Markham, Tom Videen, Paul Kotzbauer, and Hugh Flores. This study has been entirely funded by the St. Louis Chapter, and we are now seeking additional funds from the NIH.

We also continue to participate in several large studies to identify genetic factors that contribute to development of PD. Our collection of blood samples to permit extraction of DNA has made a number of new research projects possible. In fact, we recently collaborated with Drs. Alison Goate and Andy Singleton (at NIH) to investigate the effects of a series of gene defects that may contribute to PD. A paper describing these results has been published in the journal, *Nature Neurogenetics*. We found that a genetic abnormality in the DNA that codes for the production of alpha-synuclein in the brain (remember that is the protein that forms Lewy bodies) contributes to the risk of having PD. We continue to share our research findings with other investigators around the world to accelerate the rate of progress in this area. This work continues with the help of our faculty asking each of our patients to donate a blood sample for this research. Of course, the real work is done by Ling Yan, Phil Lintzenich, Stacy Pratt, Susan Loftin, Johanna Hartlein, Mark Watson, and Rakesh Nagarajan.

We have been making additional progress in our study of a new drug that may slow the progression of Parkinson’s disease. These studies have been done

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## DREAM TEAM

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in collaboration with Dr. Laura Dugan, who is at the University of California in San Diego. She discovered the new drug that we are testing and continues to work with us on the project. We have done the work at Washington University without knowing which research subjects received the active drug and which received the placebo (or fake drug). The data collected has now been completed, and the data analysis is currently being done by Dr. Dugan's team at UCSD. Next year's newsletter should have an answer about this exciting new area. This work was initially supported by the chapter and more recently has been supported by an NIH grant.

Amazingly, this is not an exhaustive list of our PD research at Washington University but rather just the "highlights reel." There are many other exciting new studies under way – investigating the causes of PD, the changes in brain function using new methods, developing new measurements of brain function to help understand the changes that occur in PD, and testing new treatments. Next year's summary article will include descriptions of some of these new areas. Remember: Advances in treating PD start with an idea, but an idea is only an idea without support to test it. You have provided that support by volunteering for research projects and donating funds to the St. Louis Chapter.

I want to thank all of you who have volunteered for our studies. Without you, this work could not move forward. I also want to recognize and thank the Greater St. Louis Chapter of the APDA and all of the donors for their continual financial support. I know that this is a tough economic time, but your support has helped us advance PD research. The teamwork among the St. Louis Chapter, its committed Board of Directors, the volunteers, the National APDA, and our other supporters like the National Institutes of Health makes this progress possible. We ALL thank you. ■

# THE UPS AND DOWNS OF DOPAMINE: IMPULSE CONTROL AND PARKINSON'S

An Interview with Dr. Daniel Weintraub

For people with Parkinson's disease (PD), managing the disease often comes down to a daily balance of dopamine—the neurotransmitter that is lost in PD. The challenge is to work with dopamine replacement therapies to find a balance between high and low levels.

Dopamine medications have improved life for millions of people worldwide. But now there is evidence that the vital neurotransmitter that eases PD symptoms can also work against them. Over the past 10 years, there has been increasing discussion in the PD community about impulse control disorders (ICDs), a phrase that is used to describe unhealthy levels of gambling, shopping, eating and sexual activity. Researchers think that some people with Parkinson's who exhibit these behaviors may be experiencing a side effect of some of the dopamine replacement therapies used to treat Parkinson's disease.

Are you concerned that you or a loved one may be affected? How can you identify these behaviors and talk to your doctor about them?

To answer these and other questions about ICDs, PDF News & Review sat down with Daniel Weintraub, M.D., a Parkinson's clinician and researcher from the University of Pennsylvania. Along with several of his colleagues, he compiled the largest study of ICDs ever conducted and the results appear in the May issue of Archives of Neurology.

## What are ICDs?

### *What are impulse control disorders in Parkinson's disease (PD)?*

In Parkinson's, the term "impulse control disorders," or ICDs, is commonly used to refer to a group of behaviors—gambling, shopping, eating and sexual behaviors—that are compulsive or impulsive in nature. While patholog-

ical gambling has been the main focus in PD, our report and other scientists have now demonstrated that all four are relatively common.

### *How common are ICDs among people with Parkinson's?*

Our study demonstrated that, when measuring at one point in time, about 14 percent of people with PD experience one or more of the four behaviors mentioned above. We believe the true prevalence for these behaviors occurring anytime during PD may be higher—my personal guess is that it's between 15 and 20 percent. Additionally, we found that if a person experienced one ICD, he or she had a 25–30 percent chance of experiencing two or more.

When we compared men and women, we found that both groups experience ICDs generally and compulsive gambling at similar rates. However, we found that men are more likely than women to have issues with sexual behavior, whereas women are more likely than men to experience compulsive buying and eating.

### *How do ICDs impact the lives of people with PD?*

There is a wide range. For some people, ICDs may be mild, or just a minor nuisance (for example, increased focus on eating sweets with a 10-pound weight gain). This group may be reluctant to make any changes to their PD medications because they value the medication's benefits over relatively minor ICD symptoms.

For others, the impact of ICDs may be more severe. People who experience compulsive gambling and compulsive shopping may lose large sums of money, even to the point of bankruptcy. Those who binge-eat may experience significant weight gain, causing discomfort

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## UPS & DOWNS OF DOPAMINE

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and embarrassment and possibly increasing vascular disease risk factors. And some of those who experience compulsive sexual behaviors may begin engaging in unprotected sex or sex outside of an established relationship, placing themselves and others at risk physically and emotionally. ICDs typically impact not only the person living with PD, but also his or her loved ones.

### Medications Linked to ICDs

*Is it true that Parkinson's medications cause ICDs? Can you explain why?*

We think that because people living with Parkinson's so often have long-term exposure to dopamine replacement therapies, some may develop hypersensitivity. Hypersensitivity may in turn lead a person to "overreact" to medications. One common form of this overreaction is dyskinesia, the twisting and writhing movements that some people with PD experience. ICDs may be another example of how the body overreacts to a dopamine medication.

*Which medications are linked to ICDs?*

The focus to date has been on two classes of medications—dopamine agonists, and levodopa, the gold-standard anti-PD medication that is usually taken as Sinemet®. In our recent study, my colleagues and I found that ICDs are most strongly associated with dopamine agonists. The two most commonly used by people with Parkinson's, and which we studied, are pramipexole (Mirapex®) and ropinirole (Requip®).

We also found that ICDs were relatively common in people taking pergolide (Permax®), an agonist no longer prescribed in the United States. Our study suggested that levodopa may also be associated with ICDs. But the odds of having this problem are less likely with levodopa use than with use of dopamine agonists.

A less frequently used medication called amantadine (Symmetrel®), is

under suspicion as well. However, some studies have suggested it may actually be effective as a treatment for pathological gambling in PD, so more research is needed.

*Will a person develop an ICD immediately after beginning one of these medications?*

Sometimes a person will experience an ICD months after beginning a medication, but often there is a significant lag time of a year or more. My sense is that most people with an ICD know that something is different, but they may not see it as a significant problem or attribute the same importance to it as their loved ones will. For example, if a man experiences a higher than normal sex drive, he may think that it is still normal, but his wife may see it otherwise.

### Treating ICDs

*How do you treat ICDs?*

The most common treatment is to lower the dosage of or to remove the medication that has caused the problem, presumably the dopamine agonist. In mild to moderate cases, a person may elect to stay on his or her medications, but in moderate to severe cases, the doctor will feel obligated to take that person off of it completely.

*Do ICDs disappear entirely when the medication is removed? How long does it take?*

My anecdotal answer is that ICDs "usually" subside for people who clearly did not experience the ICD previous to that time and developed it in the context of taking a dopamine replacement therapy for Parkinson's. I have treated people who said they felt back to normal within a matter of days to a week, and others who said the change took weeks or months. There is a much smaller subset of people for whom ICDs persist despite the discontinuation of medications.

There is another subset of individuals for whom going off a medication is not

an option. Perhaps their symptoms are too severe, or they're receiving psychological benefit from the medication. Recent research suggests that some people may experience withdrawal symptoms when going off medications. I haven't yet seen this in my own practice, but it's something I now consider when removing medications from a regimen.

*Are there additional treatments for those individuals?*

People who have significant motor fluctuations and have lived with PD for several years may be candidates for deep brain stimulation (DBS) surgery. Since a person can typically decrease his or her medications after DBS, this often will ease his or her ICD. A few other strategies have been explored, such as use of antidepressants, but there is little evidence at this point of their efficacy.

Scientists are also investigating novel treatments to resolve ICDs. My colleagues and I are studying an opioid antagonist called naltrexone. Other teams are studying a class of medications called glutamate antagonists, but the evidence on these strategies is limited at this point.

### ICDs and You

*What does the future hold for diagnosing and treating ICDs in people with Parkinson's?*

We hope the new compounds under investigation will help to treat ICDs, or that the newer dopamine replacement therapies may not have ICDs as a complication. In addition, I think we need to develop tools to improve diagnosis and care. I am a psychiatrist, so it is easy for me to discuss ICDs as part of every single visit, but not all people with Parkinson's have access to a psychiatrist. Their neurologists may be saddled with many other issues to cover during an appointment.

In these cases, it would be helpful to develop screening instruments, such as surveys that can be self-completed by people with Parkinson's and their fami-

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## UPS & DOWNS OF DOPAMINE

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lies in the waiting room. These would provide the doctor with data that they might not have the time to gather during the visit. In 2009, we published a self-complete questionnaire called the QUIP in Movement Disorders. It takes less than five minutes to complete and is available for doctors to use in their clinical practice.

### *Should people with Parkinson's be concerned about their risk of developing ICDs?*

I think they should be aware that these side effects exist and be attuned to any change in behavior, or pre-occupation with a new behavior. For example, increased Internet use (of gambling or adult websites) could be a sign of compulsive gambling or sexual behavior, but

this doesn't mean everyone using the Internet has a problem.

### *How can people living with Parkinson's and their families bring up this topic with their doctors?*

I think clinicians have an obligation from day one, when they are prescribing dopamine replacement therapies, to let people know—not just about ICDs—but about the whole range of side effects that can occur with levodopa and dopamine agonists. This would include other non-motor effects, such as sleepiness and the potential to develop hallucinations.

I tell my patients that I want them and their families to be aware that a subset of people with Parkinson's may

experience changes in gambling, buying, eating and sexual behaviors. I encourage them to talk to me about any changes in behavior. Similarly, I would encourage all people with PD, along with their families, that if they have noticed any change in such behaviors, to bring this up immediately with their physicians. ■

*This article was originally published in the Fall 2010 edition of the Parkinson's Disease Foundation (PDF) newsletter, News & Review. It is reprinted, in its entirety, with permission from PDF.*

## SURVEY FOR DBS SUPPORT GROUP – NEW DIRECTION

Maintaining attendance of any monthly meeting requires constant effort to renew the interest of the attendees. This can be quite a challenge. In an effort to make the DBS Support Group more accessible to those who have had the surgery and potential DBS surgery candidates, we are asking you

to complete the following survey. You do not have to put any identifying information on this form, but we would very much appreciate your thoughtful input. Thank you in advance for sharing your thoughts if you have had DBS or are contemplating having the surgery.

*Have you ever attended the DBS Support Group?* (yes) (no)

*What would you like to hear about in these meetings?* \_\_\_\_\_

*Are you interested in participating in a special support group as a DBS patient or candidate for the DBS surgery?* (yes) (no)

\_\_\_\_\_

*If not, what keeps you from attending the meetings?* \_\_\_\_\_

\_\_\_\_\_

*What time works best for you?*

*Day of the week:* M T W TH F SA SU

*Time:* (morning) (afternoon) (evening)

*Where did you hear about the DBS support group?*

(physician) (newsletter) (website) (family/friend) (other)

*What is the best way of communicating with group members?*

(email) (phone call) (regular mail)

*Who would you like to lead the discussions?* \_\_\_\_\_

*Location:* (north county) (south county) (west county)

(St. Louis city) (St. Charles area) (Illinois)

*What format of meetings do you prefer?*

(lecture) (question/answer) (attendee initiated)

(prearranged agenda)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

■ Please mail your completed survey to APDA, Campus Box 8111, 660 S. Euclid Ave., St. Louis, MO 63110 ■  
or fax it to 314-747-1601.



# MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Cape Girardeau	Cape Girardeau	The Chateau Girardeau 3120 Independence St.	Feb. 1, Aug. 2	3:30 PM	Desma Reno, RN, MSN	573-651-2939
		St. Francis Med. Ctr. 211 St. Francis Dr. SFMC Cafeteria	May 3, Nov. 1	6:00 PM		
Chesterfield	St. Louis	APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168	1st Tuesday	10:30 AM	Lisa Ackerman Lynda Wiens	314-725-1888 636-537-5455
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Doris Heuer Mary Green	573-815-3718
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Julie Berthold Paula Simmons	314-355-6100
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Monday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	St. Johns Regional Medical Ctr. 2931 McClelland	Mondays	1:30 PM	Nancy Dunaway	417-659-6694
Kirkwood	St. Louis	Kirkwood United Methodist 201 W. Adams	1st Monday	7:00 PM	Terri Hosto, MSW, LCSW	314-286-2418
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
Oakland/ Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
Sedalia	Pettis	First Christian Church (Disciples of Christ) 200 South Limit	3rd Monday	4:00 PM	Barbara Schulz	660-826-6039
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
St. Peters	St. Charles	1st Baptist Church of Harvester 4075 Hwy. 94 S.	1st Tuesday	1:00 PM	Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem.Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Grifford	573-543-2162
St. Louis	St. Louis	Pre/Post-DBS <b>Sunrise on Clayton Senior Living</b> <b>7920 Clayton Rd.</b>	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



# DELAY THE DISEASE – FUNCTIONAL FITNESS

David Zid

## *Posture (Floor Exercises)*

### TV POSE

Lie face down on the floor. Prop your upper body up on your elbows (like you are watching TV) with your head held high, looking forward. You should feel a slight arch in your back. Hold for 30 seconds; work up to 2 minutes if possible.

### BACK LINEUP

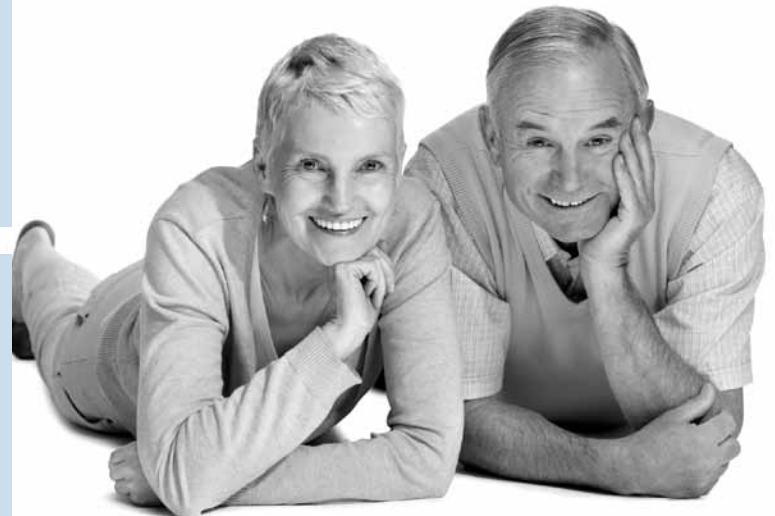
Lie on back, face up with legs as straight as possible, arms above the head on the floor. Progressively push heels, then knees, hips, low back, shoulders, head, elbows, and finally hands into or towards the floor. Hold this position for several seconds, then relax. Repeat this exercise in reverse order, starting with hands and ending with heels.

### SEATED STRETCH

Sit on the floor, with your hips close to the wall. Push your head and shoulders into the wall; push your legs into the floor. Relax your hands in your lap, toes pointed toward the ceiling. Hold for 2 minutes, relax and breathe.

### SWIMS

Lie face down on the floor. Make a fist with one hand and rest your chin or forehead on it. Outstretch the other arm; lift that outstretched arm and the opposite leg 4-6 inches off the floor. Return arm and leg to starting position. Repeat 5-10 times. Repeat on the opposite side.



Because posture is so important, I want to add some floor exercises to help combat that “vulture” pose. Perform these in addition to the standing exercises for posture, and the “vulture” should vanish. Good luck and stand tall. ■

## WANTED:

## PARTICIPANTS FOR A NEW WEST COUNTY EXERCISE CLASS

A new exercise class for people with Parkinson’s (PwP) is scheduled to begin at The Cedars at JCA on Thursday, November 11, 2010, and every Thursday afternoon from 2:30 p.m. – 3:30 p.m. under the direction of Faye Bienstock, PT, Program Director of the Therapy Department.

The Cedars at the JCA is located at 13190 South Outer 40 Rd., Chesterfield, MO 63017.

From *westbound* Highway 40/64:

- Exit Maryville Centre Dr (exit 23)
- Go south (left) over the highway
- Turn left on S. Outer 40 Rd.
- Continue 3/4 of a mile to The Cedars at the JCA

From the *eastbound* Highway 40/64:

- Exit Mason Road (exit 24)
- Merge onto S. Outer 40 Road.
- Continue east on S. Outer 40 Road for 6/10 mile to The Cedars at the JCA.

Turn into the second gate and drive through the Main Entrance, continuing until you reach The Plaza Building. You will have exercise class in the Grand Symposium room in the Plaza Building. Enter the building and proceed straight ahead to the Grand Symposium room.

We are hoping that by adding this third West County exercise class, we can eliminate the waiting list at St. John’s Rehabilitation and St. Luke’s Hospital

and provide yet another opportunity to exercise on a weekly basis. Should you wish to add a second day of exercise to your weekly regimen, you may do so (providing there is room in the class) at the cost of \$20 per month. All PwP are provided the first weekly exercise class free of charge, but are charged \$5.00 per session for attending a second class each week. Please contact Cherstin Byers at 314-362-3299 or [byersc@neuro.wustl.edu](mailto:byersc@neuro.wustl.edu) if you wish to enroll in two exercise sessions per week. ■



# ILLINOIS SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Mary Friedrich Jodi Gardner	618-234-4410 x7031 or 7033
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Tom Hippensteel	618-684-4282
Carmi	White	Phoenix Rehab. & Nursing 615 West Webb St.	4th Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 PM	Cathy Watts	217-428-7716
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Matoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Marcia Smith	217-254-4869
Mt. Vernon	Jefferson	Greentree of Mt. Vernon, 2nd Floor	4th Thursday	6:30 PM	Donna & Bill Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr.	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Dan Vonberg	217-546-2125

## WOULD YOU LIKE TO DANCE?

Gammon M. Earhart, PhD, PT  
Assistant Professor of Physical Therapy, Anatomy & Neurobiology, and Neurology, Washington University in St. Louis

I am very pleased to report that the St. Louis Chapter of the APDA has generously agreed to continue their support of tango classes for people with Parkinson disease (PD) and their caregivers. This support comes on the heels of several years of APDA-supported research conducted in my laboratory. Since 2006 we have been studying the benefits of dancing Argentine tango for people with Parkinson disease (PD). To date we have published nine research articles highlighting the many benefits of tango dancing, including improved balance, walking, and quality of life. All of these papers examined the benefits of short-term participation in tango for a period of three months or less.

Our most recent and ongoing study, funded by the Parkinson's Disease Foundation, aims to determine the long-term benefits of dancing tango. Since this time last year, a dedicated group of people with PD and their caregivers and friends have been dancing tango twice a week. Prior to starting the dancing, and after three and six months of dancing, participants with PD underwent thorough evaluations of their



mobility, quality of life, and disease severity. All of these assessments have been performed off medication; i.e., participants stop taking all anti-PD medication for at least 12 hours before completing the evaluations. This allows us to assess each person's status without the confounding influence of medications. Those dancing the tango are being compared to a group that is not performing any specific exercise. Although we are still gathering data to complete this study, our preliminary *continued on next page*



# EXERCISE CLASSES

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	Barnes Extended Care 401 Corporate Park Dr.	Wednesday & Friday	1:30 PM	Sue Tucker, OT Mike Scheller, OT	314-289-4325
Chesterfield	St. Louis	St. John's Mercy Rehabilitation Hospital 14561 N. Outer 40	Tuesday	1:00 PM	Deb Luetkemeyer, PT	314-881-4200
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	10:30 AM	Patty Seeling, PT	314-205-6934
<b>Chesterfield</b>	<b>St. Louis</b>	<b>The Cedars at JCA</b>	<b>Thursday</b>	<b>2:30 PM</b>	<b>Faye Bienstock, PT</b>	<b>314-754-2180</b>
Creve Coeur	St. Louis	Rainbow Village—Aquatic Exercise 1240 Dautel Lane	Thursday Oct. 7 – Dec. 16	2:00 PM	Brenda Neumann	636-896-0999 ext. 312
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Sue Tucker, OT Mike Scheller, OT	314-289-4325
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Ste. 117	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, PT	636-916-9650
St. Peters	St. Charles	Aquatic Exercise—St. Charles YMCA 3900 Shady Springs Ln.	Thursday Oct. 7 – Dec. 16	2:00 PM	Brenda Neumann	636-896-0999 ext. 312
North St. Louis County	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534
St. Louis City	St. Louis	The Rehab. Institute of St. Louis 4455 Duncan Ave.	Thursday	Noon	Janelle Davis, PT	314-658-3858

## TANGO CLASSES

*continued from previous page*

inary results are exciting and suggest that dancing tango for a period of six months or more may modify the progression of the disease (as assessed by a standard neurological examination of the movement problems associated with PD). Those who have been dancing show less severe motor symptoms after six months of tango than those who are not exercising, even though both groups started at the same level. In addition, those who are dancing have made substantial gains in other areas including balance, walking, and quality of life. All of these gains have been larger at six months than at three months, suggesting that longer participation in tango results in greater benefit. We are anxious to see the results we obtain after 12 months of dancing.

While the data are interesting, per-

haps nothing speaks as strongly as the words of those who have participated in this class. Here are a few examples of what people have to say about their experiences. A caregiver reports, "The most positive outcome of his PD diagnosis has been his involvement in Tango. Dancing increases his mobility, improves his balance, and provides the best possible support group for both of us. We leave each lesson feeling better about life and more confident that we can meet its challenges." A husband and wife team says, "We enjoy the classes immensely and look forward to them each Monday and Thursday. They are even more than we expected. Not only do we feel that they have slowed the progression of the disease, but they have also enhanced the quality of our lives and our relationship. Everything we had read indicated that fighting the disease would be a team effort between the Parkinson patient and

the caregiver. We were prepared for the challenges of this effort but were not expecting that working together could be so enjoyable. Tango classes are fun and have brought us together in an activity we can do together to overcome the disease."

Our study will be completed in December, at which time we feared that the tango classes would come to an end. However, thanks to the generous support of the St. Louis Chapter of the APDA we will continue to offer tango classes throughout 2011. Beginning in January, these classes will be held at the Crestwood Court Mall on Monday and Thursday afternoons from 3:00 p.m.-4:00 p.m. Space is limited, and the class will be filled on a first-come, first-served basis. If you are interested, please contact the St. Louis Chapter APDA office at 314-362-3299. ■

# 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](http://www.stlapda.org), by clicking on the **Donate** link (on the right side of the home page).

## HONORING

*Our researchers who participated in the APDA National Presidents & Coordinators Conference: Drs. Willis, Racette, Perlmutter, Tabbal & Earhart*  
Debbie Guyer

*The Speedy Recovery of Monte Abrams*  
Harvey & Lee Shapiro

*The 50th Wedding Anniversary of Kay & Denny Anstine*  
Lillian & Jack Bolozky

*Colette Marie Arnett*  
Dicey Women (Bunco Card Group)

*Honoring our 50th Wedding Anniversary*  
Kay & William Bruchhauser

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Jack & Josefina Schrader  
Marcia Schrader

*Bill Donius – Honorary Chairperson of the Fashion Show*  
Debbie Guyer

*The Special Birthday of Elinor Eidelman*  
June Laba

*Virginia R. Glennie*  
Donald G. Glennie

*Debbie Guyer – recipient of the 2010 Salvatore A. Esposito, Sr. Award from National APDA*  
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*The Special Birthday of Neil Handelman*  
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*The 50th Wedding Anniversary of Dan & Judy Huddleston*  
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*The 25th Wedding Anniversary of Joseph & Susan Rechter*  
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*continued on back page*

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Congratulations and our deep appreciation to the 20 committee members who went from shop to shop and restaurant to restaurant collecting items and gift cards for our auction.

Congratulations and our sincere thanks to the boutique owners who selected fashions from their racks and fit our models for the show. Congratulations and round of applause to our 49 beautiful models who walked the runway in fashionable attire.

Heartfelt thanks to our reservation volunteers, bankers, and runners who made sure that the event progressed smoothly for our 375 guests. Our gratitude is extended to the 180 donors who so generously contributed gift items for the baskets, one-of-a-kind items for our raffle, and wine for our centerpieces. It all came together for one of our most successful fundraisers, and you all had a role in our success.



# Life is a Cabernet

Lynda Wiens again made baskets that are the envy of every other gift basket-maker in St. Louis. Tracy Wright constructed a beautiful show featuring a team of volunteers, radio and TV personalities. Kent Ehrhardt and Victoria Babu kept the commentary running

and amusing as co-emcees. The meaningful and PD-related Tango dance was performed in between runs to entertain us. It all came together like pieces in a puzzle. Bill Donius inspired us all and made us remember why we were there in the first place.

Congratulations and many, many thanks for all your help! For a complete viewing of all of the photographs taken by and courtesy of Cathy Hartman Photography and video production by Larry Balsamo (Video Views), visit our website at [www.stlapda.org](http://www.stlapda.org).



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# Fashion Show 2010 HIGHLIGHTS

