

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."

LINK

St. Louis APDA

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

APDA CENTER FOR ADVANCED RESEARCH AT WASHINGTON UNIVERSITY IN ST. LOUIS

Joel S. Perlmutter, M.D.

This has been another highly productive year for our APDA Center for Advanced Research at Washington University. The combined efforts of our growing group of faculty and staff, strengthening support from the Greater St. Louis Chapter of the APDA and ongoing support from the National APDA have contributed to this level of success. In this article I describe the progress in various research projects.



We continue to make substantial 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 as well as multiple staff including Johanna Hartlein, Dawn Lintzenich, Angie Wernle, Sandy Sagitto, Heather Lugar, Hugh Flores, Laura Carpenter, Len Lich, Patrick Weaver, Terry Anderson and others. Of course, I would be remiss if I did not point out that several students from Washington University have contributed to this work. Key advances this year include improving methods for identifying more precisely the exact location of the stimulating electrodes in the brain (working on accuracy approaching 1 mm – that is 1/25 of an inch). This increasing precision helps all of our DBS studies. We have been awarded two new grants from the National Institutes of Health (NIH) for these studies—one to Drs. Hershey and Black to investigate how mood and thinking are affected by DBS and the other to me to investigate how DBS affects movement, walking, balance and brain function measured with PET scanning. Both of these studies are now able to focus on how targeting DBS at different parts of the sub-

thalamic nucleus preferentially affects these different behaviors. Again, this is possible due to the advances in identifying the precise location of the stimulating electrodes. It is important to remember that support from the Chapter not only started these studies but continues to help us pursue new ideas and collect preliminary data that makes obtaining these new NIH grants possible.

Dr. Earhart and her bevy of graduate students have continued to investigate the effects of dance on walking and balance in people with PD with the publication of several new papers this year. The team has described the effectiveness of dance therapy including evaluations of tango and American ballroom dancing. She also has been actively studying turning problems in PD and how that may be related to freezing—when the feet suddenly stop. Her initial work in these areas has been supported by the Chapter and now this past summer obtained a new NIH grant to continue the studies of the rotating treadmill and how this may improve turning in PD. She also won a new foundation grant to continue studies of dance and how that may benefit people with PD. She continues to be a highly effective investigator and an extraordinarily gifted teacher of graduate students. As you may recall, she trained Dr. Madeleine Hackney, who was awarded her PhD for studies of dance in PD and also mentors Mike Falvo who has been working studies of walking and the effects of exercise in PD.

Dr. Racette along with Drs. Criswell, Wright-Willis, Evanoff and Checkoway continue to investigate environmental factors that may

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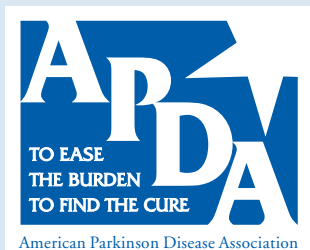
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PRESIDENT'S LETTER

Matt LaMartina

Dear Friends,
As we near the end of one of our most challenging years,

I want you to know how much I appreciate your continued support and to offer my sincere thanks for your active participation and involvement with the Greater St. Louis Chapter of the APDA. The

last 12 months have created new challenges for all charitable organizations, separate and apart from our own individual struggles in today's world. With challenges come choices. Some may retreat and hope things will improve if left alone. Others decide to confront the problems head on and find solutions. The decision made by the APDA Board of Directors of the Greater St. Louis Chapter was to continue to work aggressively with programming and research support, in spite of reduced daily individual donations. Because, in spite of the economy, people are still being diagnosed with Parkinson's disease in large numbers. Those persons who suffer from PD still need our help.

I'm proud to say that the St. Louis Chapter has worked harder than ever to continue to raise awareness and money through our two major fundraisers. Our annual Nat Dubman Memorial golf tournament was held in May and was another huge success. With the help of our honorary chair, St. Louis Cardinal GM John Mozealiak, and our small but mighty golf committee, we broke our previous record and raised more funds than ever. In addition, our annual fashion show was bigger and better than ever. The fashion show/auction committee, led by Jill Garlich and Lynda Wiens, worked tirelessly to make the event a success. A large amount of funds were raised to continue to



provide support of patient services and on-going research. I want to personally thank both committees of volunteers for their hours of work. And to all of our supporters who donated so much of their time and money to make these events overwhelming successes, THANK YOU hardly seems enough. Moreover, special thanks to Debbie Guyer for her countless hours behind the scenes on both events. We couldn't have done it without her! Wait until next year and see what we have up our sleeves!

Make no mistake, *To Ease The Burden...To Find The Cure* is our motto and we live it every day. The funds raised by the Chapter this year helped to expand our patient services in several ways. We added new and improved programs to our already strong line up (aquatic exercise classes, dance classes, new exercise classes and an array of special lectures open to the public) and we were able to expand demographically (across the state of Missouri and into southern Illinois) and touch more people with Parkinson's disease and their families who live with this disease every day. In addition, we contributed more research dollars to our team of Movement Disorders specialists at Washington University School of Medicine who work day in and day out to find the cure for PD.

I'm certain 2010 will again provide yet a new set of challenges to our organization. But I am confident in saying we will face those challenges head on and with your help succeed in our mission. Please feel free to contact me with any concerns or suggestions you may have as we move forward into the New Year.

Best Regards,
Matthew LaMartina
President APDA St. Louis Chapter

CENTER FOR ADVANCED RESEARCH

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contribute to the development of parkinsonism. Dr. Wright-Willis just completed a study of environmental factors associated with prevalence of parkinsonism. Dr. Racette's team also has continued to investigate whether welding exposure increases PD risk, and they continue to travel to other cities to examine union members with and without welding exposure. They recently published a study on developing measurements of exposure to welding – an occupational exposure that they are studying. Drs. Criswell and Racette have brought some of these participants to Washington University for brain imaging studies using the MR and PET scanners. We have been applying new analysis methods to these scans and the work continues. Again, this is an area in which students supported by the Chapter have helped us immensely in this research. Dr. Criswell also obtained a mentored career award to help support this work and Dr. Racette also has an NIH grant supporting part of this work.

We are now in the 4th year of our study funded by the Chapter to investigate the relationship of dementia with PD and have made substantial progress this year. People with PD are at increased risk for developing trouble with memory, concentration and problem solving. These difficulties, called dementia, are symptoms commonly caused by Alzheimer's disease. In people with PD, dementia may be caused by Alzheimer's disease or can be caused by a condition known as Lewy body disease. Lewy bodies are abnormal clumps of protein found in selected parts of the brain in PD and when these Lewy bodies are also found widely distributed they may cause thinking problems. Currently, the only way to determine the precise cause of dementia in someone with PD is to examine the brain under the microscope – a test done only after someone dies. Our study is to determine if

a new type of PET scan can help us distinguish these different types of dementia. We just found that the PET scan, called a PIB PET scan, may reveal new insights into the changes in the brain causing dementia. This finding is not exactly what we expected and the only reason that we have made this discovery is that many people have volunteered for these studies. Each has volunteered not only for a series of thinking tests, an MR scan of the brain and PET scan of the brain but also agreed to permit us to examine the brain after death. This brain donation has been the critical step in this research. The results of this part of the study will be published soon. In addition, we are now preparing another paper for publication. So we are on a roll. In addition to our volunteer participants, several members of our team have worked on this study: Erin Foster, Meghan Campbell, Michelle Burack, Nigel Cairns, Tamara Hershey, Johanna Hartlein and others. This study has been entirely funded by the St. Louis Chapter of the APDA.

We also continue to participate in several large studies to identify genetic factors that may 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 submitted for publication. We also continue to work with lots of others around the country to pool our resources for these studies that at times require many thousands of DNA samples. This work continues with the help of our entire faculty asking each of our patients to donate some blood. Of course, the real work is done by Laura Carpenter, 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 disease. These studies have been done

in collaboration with Dr. Laura Dugan, who is now at the University of California in San Diego. She had discovered the new drug that we are testing and continues to work with us on the project. Our early data are quite enticing but we need to complete a couple of years of additional work to confirm these preliminary findings. This work was initially supported by the Chapter and then more recently has been supported by an NIH grant to me.

In summary, we continue to make progress on many fronts in our research into the causes, mechanisms and treatments for PD. This reminds me of a question I was asked when lecturing in Saskatoon recently – “will the greatest benefit for people with PD come from research into the causes of PD, its treatments or investigations of potential cures?” I explained that we need the full spectrum of research. I believe that the ultimate cure or cures for PD will grow from greater knowledge of the precise causes of PD. However, substantial improvements in treatment come from studies covering all aspects including causes, brain changes associated with PD, understanding mechanisms of treatment and testing new drugs. There is no one magic solution but rather lots of continued effort in many areas will eventually lead us to a cure.

I want to thank all of you who have volunteered for our studies. Without you, this work could not move forward. I also thank the ongoing financial support of the Greater St. Louis Chapter of the APDA. The teamwork among the Chapter, the volunteers, the National APDA and our other supporters such as the National Institutes of Health make this progress possible. And, a key part of the teamwork has been the Board of Directors of the Greater St. Louis Chapter of the APDA under the leadership of President, Matt LaMartina. Of course, Debbie Guyer, who coordinates our APDA Information and Referral Center and the Chapter, continues to grow in her passion and commitment to this program. Together, we will continue to make progress in our fight against PD. ■

YEAR-END CHARITABLE GIVING IDEAS...IT IS NOT TOO LATE!

David S. Dankmyer, JD, LLM

We all know that charitable giving provides us an opportunity to benefit a worthy charity. How would the APDA fight a disease such as Parkinson's disease without the financial help of our generous donors? A side benefit of charitable giving is that you may reap significant income tax benefits. The amount of the tax savings depends on your tax bracket and on the type of property contributed. To be sure, your charitable gift is more important than ever in making a difference to a charity such as the APDA, but getting a tax benefit does not hurt! Unbelievably, this year is almost over. Now is the time to think about making your year-end charitable contribution.

There are more gifting options to make your charitable gifts than we can discuss in this article. The following are some of the most common and impactful ways of options to make your gifts:

Cash: Keep it simple!

A gift of cash is the easiest way to make a gift and benefit a charity. The only trick is to make sure your gift is postmarked by the end of this year. Otherwise, you will not be able to deduct the gift against your 2009 income. Under current tax law, you can deduct up to fifty percent of your adjusted gross income for gifts of cash to public charities. Any excess can be carried forward and deducted over the next five years.

Double your donation...for free!

Does the company you work for match your charitable donations? To find out, check with your HR department for such a program and the details. Usually you are required to provide a receipt or letter from the charity that your donation was made and the amount. In addition, some companies and organizations will match anyone's gift. There are websites such as www.donationdoubler.org, which has a list of such organizations.

Gifts of appreciated stock.

Gifts of stock (of public companies) is an extremely tax efficient manner of making gifts. You get two tax benefits. First, the value of your charitable gift is the full market value of the stock on the day of the transfer. Second, you completely avoid paying the capital gains tax on gifted stock. A public charity does not pay income tax on the sale of the stock. Again, you must make the transfer before the end of the year to get the deduction in 2009. In addition, you need to have held the stock for more than one year to qualify for the tax benefits. Gifts of long-term capital gain stock are deductible up to a maximum of thirty percent of your adjusted gross income. A stockbroker or trust officer can very easily arrange for the transfer.

Example: You purchased 1000 shares of Apple, Inc. several years ago at \$10 a share (cost \$10,000). In October 2009, you make a gift to the APDA of the same 1000 shares at the current price of \$200 a share (\$200,000). Your deduction is \$200,000 and you pay no capital gains tax on the \$190,000 of appreciation.

IRA Charitable Rollover.

Congress actually did something very good last year! They extended the ability to transfer up to \$100,000 directly to a charity from your IRA. You must be 70 ½ or older and can count the contribution towards your required minimum distribution. More importantly, you completely avoid income tax on the amount contributed. Also, a husband and wife with separate IRAs can each contribute \$100,000.

In order to avoid paying tax on the withdrawal (which is at the ordinary income tax rates), the transfer must be made directly to the charity.

Example: Assume you wish to contribute \$100,000 to the APDA. If you make the withdrawal of a \$100,000 and it is directly payable to the APDA from your IRA, the entire amount is excluded from income. If you withdraw \$100,000 from your IRA and deposit in your checking account, the entire \$100,000 is included in your taxable income and you pay tax at the ordinary income rates.

There are many other ways to make tax advantaged gifts to a charity such as gifts of life insurance, real estate, cars, etc. You should consult your CPA or tax attorney for other options before making charitable gifts. In addition, the charity receiving your gift must be a "Qualified Charity" as defined by the Internal Revenue Code in order to receive the tax benefits. Again, your CPA or tax attorney can give you guidance.

(If you have any further questions, please feel free to call David Dankmyer at 314-862-5190.)

RESEARCH STUDIES

Dr. Gammon Earhart is currently looking for people interested in participating in two different research studies. One study is examining the effects of dance on balance and walking and involves participation in a year-long tango class. This study is funded by the Parkinson's Disease Foundation. The other study examines balance, walking, and quality of life across time, with participants coming in every six months for a full evaluation. Washington University is one of four sites across the country conducting this study, which is funded by the Davis Phinney Foundation. The study aims to learn more about changes in quality of life, mobility and exercise habits over the course of the disease. For more information about how you can participate in either study please call Dr. Earhart's laboratory at **314-286-1478**.

OPEN ENROLLMENT FOR MEDICARE PRESCRIPTION DRUG PLAN: WHAT CURRENT AND FUTURE ENROLLEES NEED TO KNOW

John R. Schmeling, MSW Intern

Over the past three years the Medicare Prescription Drug Plan has helped to make medications more affordable for many Medicare recipients. However, with changing formularies, escalating premiums, and other factors, choosing a plan for new enrollees and deciding whether to remain with your current plan can be a confusing task.

For those enrollees who are happy with what their plan offers, but discouraged by the increase in premium costs, here is some information to consider. The top six prescription plans, with the most enrollees, have seen higher than average increased premiums in the last three years. For about a quarter of enrollees, premium increases will amount to over \$120 for the year.

Some programs that offered the lowest premiums when Medicare prescription drug coverage began have doubled and in some cases quadrupled in the past three years. So it is worthwhile to take the time to compare plans and consider switching if another plan meets your needs at a lower price.

Each year from November 15 to December 31 is Open Enrollment, when all enrollees have the opportunity to compare plans and then switch plans if they choose. Luckily there are resources to help individuals compare plans and assist enrollees in making the best choice for them. When comparing plans that best meet your needs consider the following:

Factors to consider when evaluating a plan

- The amount of the monthly premium
- Whether the plan's formulary includes or continues to include your prescriptions

- If the plan has a deductible
- The amount of co-payment for each of your prescriptions (may be affected by which so-called "tier" it is under)
- Whether the plan's network include pharmacies used by you, including mail order pharmacies



- How the plan coordinates with the State Pharmaceutical Assistance Program

When comparing plans it is important to examine several factors. Lowest premium or deductible may not be the best value when compared to the total costs for the entire year. To help individuals decide, the Medicare website offers a tool for comparing plans.

What you need before comparing plans

- A list of your medications, daily dose and times per day
- The name of your preferred pharmacy or others in your area
- Information on your current plan (co-pays, deductibles, and premiums)
- It is helpful to have an idea of your current pharmacy costs

Comparing Prescription Plans

If you are computer savvy or have someone to assist you simply go to [Medicare.gov](https://www.medicare.gov), scroll down to **Search Tools**, and click on the **Compare Medicare Prescription Drug Plans** link. This allows you to input your prescriptions and compare plans based on deductibles, co-pays, premiums, and other categories such as total yearly out-of-pocket costs.

If you would prefer to speak to someone by phone you can contact Medicare at **1-800-MEDICARE (1-800-633-4227)**. Also, your local Area on

Aging has volunteers that can assist in comparing plans, they can be located by calling **1-800-677-1116** or at www.eldercare.gov.

The Doughnut Hole

While Medicare Part D programs help with the cost of prescription drug costs, there is a point known as the coverage gap or "doughnut hole." It is important to remember that not all enrollees will fall into the "doughnut hole." However, when an enrollee moves into the "doughnut hole" they become responsible for 100% of drug costs until reaching the out-of-pocket expense limit where they then qualify for catastrophic coverage. If you find yourself in the "doughnut hole" here are some suggestions and resources that may help curb out of pocket expenses.

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OPEN ENROLLMENT

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5 ways to lower drug costs during the “doughnut hole”

1. Consider switching to generics or other lower-cost drugs.
2. Explore national and community-based charitable programs (benefitscheckup.org).
3. Look into pharmaceutical assistance programs (needymeds.org and www.medicare.gov/pap/index.asp).
4. Look at state pharmaceutical assistance programs (23 states currently).
5. Apply for extra help—(www.socialsecurity.gov) savings of up to \$3900 for those eligible for low-income subsidy.

Extra Help

For those interested in the low-income subsidy or those who may have been denied in the past, two important changes are coming in 2010. After January 1st life insurance policies will no longer be counted as a **resource**, and help you receive regularly from someone else to pay your household expenses will no longer be counted as **income**. For those who have been previously denied, Social Security should begin sending mailers in February 2010 to let you know that you now may be eligible. For further information on the low-income subsidy contact the Social Security Administration at www.socialsecurity.gov or by phone at 1-800-772-1213.

Other Websites with Helpful Information

- <http://www.medicare.gov/bridging-the-gap.asp>
- <http://content.nejm.org/cgi/content/full/361/4/406>
- http://www.medicareadvocacy.org/FAQ_PartD.htm#exceptions
- <http://www.benefitscheckup.org>
- <http://www.medicare.gov/pdp-things-to-consider.asp>
- <http://www.kff.org/medicare/upload/7835.pdf> ■

USE OF PIB PET IMAGING TO EVALUATE DEMENTIA SUBTYPES IN PD PATIENTS

Meghan Campbell, Ph.D., Joel Perlmutter, M.D., Principal Investigator

The purpose of this study is to determine the cause(s) of dementia in Parkinson's disease (PD). The most likely causes of dementia in PD are Alzheimer's disease or dementia with Lewy bodies. To differentiate between these two possible causes of dementia, we are using a novel Positron Emission Tomography (PET) tracer that is thought to be sensitive to the brain changes associated with Alzheimer's disease. Participants also complete neuropsychological and motor assessments. Our goal is to be able to distinguish between these different types of dementia in PD to aid in the development and application of new treatments.

Study Update

To date, over 50 individuals have enrolled in this study and we hope to enroll another 25 individuals over the next year. Preliminary findings have been presented at several conferences and we are currently working on publishing these initial results.

We are still recruiting!

- We still need additional participants for this study. There are three groups of study slots which we need to fill.
- We are most interested in people with idiopathic PD, age 55 or older, WITH changes in memory & thinking function. In fact, we are particularly interested in learning more about individuals with idiopathic PD who noticed cognitive changes before or shortly after motor symptoms began.
- We are also interested in people with idiopathic PD, age 55 or older WITHOUT any change in memory or thinking function.
- We are lastly interested in people WITHOUT idiopathic PD or other neurological disorders and

age 55 or older to participate as a control group for this study.

What does the study involve?

1. A detailed assessment of memory and thinking function and a physical examination
 - a series of tests that measure different aspects of memory and thinking function (~90 minutes); these must be done while “off” of iPD medication
 - interview of a family member or friend who can provide information about memory and thinking function in everyday life (~45 minutes)
 - assessment of Parkinson disease symptoms
 - agreement that you will return on a yearly basis for memory and thinking assessments
 - *Please note that there is a shortened version of the memory and thinking tasks that can be done for individuals whose memory and thinking problems are moderate to severe.
2. A brief MRI scan (~15 minutes) and a PET scan (~1.5 hours)
3. Consent for brain donation after death

What are the benefits?

1. A free evaluation of memory and thinking.
2. Reimbursement for your time and travel.

What are the costs?

None. All procedures are for research purposes only and there is no charge to you or to the insurance company.

If you are interested, please contact our research nurse coordinator, Johanna Hartlein, MSN/APN:

Email: Johanna@npg.wustl.edu
Phone: 314-362-0420 ■

COMPULSIVE BEHAVIORS IN PD

Joseph H. Friedman, MD

Introduction

The first report of a repetitive behavior disorder associated with Parkinson's disease (PD) was published in 1995 by me. I think it got published because I used the term "punding" in the title, which attracted the attention of the reviewers who never had heard of the word.

"Punding" means "blockhead" in Swedish, and is a term used by amphetamine addicts to describe a very peculiar behavior that some of them developed during the height of their addiction. They would become relatively immune to the concerns of the world and become entirely consumed doing a limited behavior over and over again, generally taking things like flashlights and electronic equipment such as radios and tv's apart and putting them back together. As you can imagine, the putting together part of this equation was not so good as the taking apart. They didn't like to be disturbed while doing this, and it might go on for many hours at a time. This is an obsessive sort of behavior, and I identified a small number of my PD patients who described having similar problems. One was a bookkeeper who could not keep from tallying the same set of figures over and over again although his tallies, back in the days before computers did these things, were always the same. Another couldn't stop from reading the entire label of cans in the supermarket, and another couldn't stop trimming her bushes. I had come across punding while writing an article on something else, but made the important biochemical connection that amphetamines increase dopamine secretion, which is, of course what L-Dopa does in PD, so that the occurrence of punding in PD should not have been unexpected.

The importance of the punding problem in PD was not recognized, and here I blame myself, until the early 21st century when some astute observers

noticed that some of their PD patients had developed problems gambling and this appeared to be related to their dopamine agonist drugs (bromocriptine, pergolide, pramipexole, ropinerole, rotigotine, lisuride). It also turned out that the patients I had described with punding, which I blamed L-Dopa for, were all also taking dopamine agonists.

Repetitive Behaviors

It is now well known that patients taking dopamine agonists, and less commonly L-Dopa alone, may develop a problem with gambling, hypersexuality, excessive spending of money, uncontrolled eating or a number of other addictive behaviors. The terminology used to describe this collection of activities varies because no one is sure exactly how to categorize them. At their core, these are addictive behaviors. Patients do something over and over again, so they are repetitive behaviors. The patients describe feeling compelled to do something, so they are compulsive disorders. Once they have the idea that they should do something, they act impulsively, so they are impulse control disorders.

In the dopamine dysregulation syndrome, patients act like they are addicted to L-Dopa. They take extra pills whenever they can even though they are already dyskinetic, a sign that usually indicates over-medication. They cannot tolerate even a minute or two of "off" time, just like a heroin addict cannot tolerate pain or the lack of being "high." These patients crave whatever feeling the L-Dopa provides, even if it causes them to hallucinate, become paranoid, or behave in ways that cause trouble to themselves and others (for example, my patient who got arrested several times for trying to "party" with his neighbors at 3am several times). Once his pills were taken away from him so



that someone else administered them, he hoarded them, pretending to take them, accumulating a stash and then got his "high."

The most common of these types of disorders is gambling. People who never had gambled suddenly became a little interested and would start to visit casinos, or buy scratch tickets or bet on horses. At the beginning it was a new interest and was not a problem; however, it would become increasingly out of control. Unlike most drug side effects, the behavior was not seen as foreign. The patients did not make the connection with the drug, because it usually

began long after, maybe months or years, the drug was first started, and, of course, there was no abnormal feeling—they weren't dizzy, or foggy, or lightheaded. They simply had developed a new interest in life, gambling. But the behavior associated with the gambling was addictive. The patients bet more than they could afford. They lied about their behavior. They denied the "high" or "rush" that the gambling caused, just like an alcoholic, crack cocaine smoker, or heroin user.

The following is part of an email I received from the adult daughter of a PD patient. She kindly consented to allow me to use this for this article.

Good evening Dr. Friedman, I'm writing to inform you of some recent changes in my father's health both physically and psychologically. He seems to be out of control. He is gambling everyday and yesterday we found out that he has dipped into his retirement funds for more money. He has nothing left and no matter how many times we tell him and show him that he has no more money left, he doesn't comprehend. As hard as my sister tries to keep a small amount

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MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted. Support Group day and time may change periodically. For current updates on support groups and exercise classes, call the APDA Information & Referral Center or the facilitator.

City	County	Meeting Site	Day of Meeting	Time	Leader	Phone
Cape Girardeau	Cape Girardeau	St. Francis Med. Ctr. 211 St. Francis Dr. SFMC Cafeteria	4th Monday	6:30 PM	Desma Reno, RN, MSN	573-331-5871
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Gerry Neely, RN	573-815-3554
Creve Coeur	St. Louis	Shaare Emeth Congregation 11645 Ladue Rd., Library	1st Wednesday	2:30 PM	Lisa Ackerman	314-725-1888
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 Kim Liefer	314-355-6100
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	St. Johns Regional Medical Ctr. 2931 McClelland	Mondays	1:30 PM	Nancy Dunaway	417-659-6694
Kirkwood	St. Louis	Kirkwood United Methodist 201 W. Adams	1st Monday	7:00 PM	Terri Hosto, MSW, LCSW	314-286-2418
Kirkwood/Oakland	St. Louis	Bethesda Dillworth 9645 Big Bend	3rd Friday	10:00 AM	Laurel Willis, BSW Shellie Eswine, BSW	314-373-7036 314-446-2186
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	5:30 PM	Patsy Dalton	573-964-6534
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	1:30 PM	Mary Harlan Richard Wagoner	573-364-6820
Sedalia	Pettis	First Christian Church (Disciples of Christ) 200 South Limit	3rd Monday	4:00 PM	Barbara Schulz	660-826-6039
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
St. Peters	St. Charles	1st Baptist Church of Harvester 4075 Hwy. 94 S.	1st Tuesday	1:00 PM	Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Riverview at the Park 21997 White Sands Rd. Solarium	2nd Wednesday	10:00 AM	Jean Grifford	573-543-2162
St. Louis	St. Louis	DBS Patients Sunrise on Clayton Sr. Living 7920 Clayton Rd.	3rd Thursday	1:00 PM	Steve Balven & Stan Wilensky	314-249-8812 314-997-5114
Chesterfield	St. Louis	Newly Diagnosed APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168	1st Tuesday	10:30 AM	Carol Feuerhahn	314-863-4725
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 1	3rd Tuesday	6:30 PM	Rich Hofmann	314-369-2624



ILLINOIS SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted. Support Group day and time may change periodically. For current updates on support groups and exercise classes, call the APDA Information & Referral Center or the facilitator.

City	County	Meeting Site	Day of Meeting	Time	Leader	Phone
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Mary Friedrich & Jodi Gardner	618-234-4410 x7031 or 7033
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Tom Hippensteel	618-684-4282
Carmi	White	First Christian Church 504 Bohlever Dr.	3rd Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 PM	Cathy Watts	217-428-7716
Granite City	Madison	St. Johns United Church of Christ 2901 Nameoki	1st Thursday	1:30 PM	Hilda Few & Karen Trim	618-797-0527 618-345-3222
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Lisa Ketchem, RN	618-664-0808 ext. 3555
Matoon	Coles	Sarah Busch Hospital 500 Health Center Dr.	Last Tuesday	1:00 PM	Kay McDade	217-258-4040
Mt. Vernon	Jefferson	Greentree of Mt. Vernon 2nd Floor	4th Thursday	6:30 PM	Donna & Bill Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr.	3rd Sunday in May, July, Sept., & Nov.	2:00 PM	Dan Vonberg	217-546-2125
Vandalia	Fayette	Fayette County Hospital 650 West Taylor, Conference Room	Last Tuesday	1:00 PM	Charlene "Pokie" Pryor	618-283-4633



EXERCISE CLASSES

Our Exercise Classes meet once a week or otherwise noted.

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

TRIBUTES & DONATIONS

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

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COMPULSIVE BEHAVIORS

continued from page 7

in the checking account to pay bills on automatic payment, he takes out that money to spend on gambling and checks and payments have bounced. He is lying to everyone to try to get pity from them and money. He lies and says he has no money for food and we always make sure he has food in the house and we buy him food and gas cards every week. He is driving at night against our wishes and we fear that he is going to harm himself and/or others. Next week we are meeting with a lawyer to see about taking over ALL financial matters.

We have been dealing with this problem for over a year. He refuses to stop his dopamine agonist because his mobility declines. His family will not allow me to stop the agonist and contacting the pharmacy to stop allowing him to renew these prescriptions, because he suffers physically off the agonist. He takes large amounts of L-Dopa in addition. He refused psychiatric hospitalization and is fully competent, legally, to do so. And he denies having a problem even as his daughters repay his debts in front of him.

Hypersexuality generally affects men, but some women too. Pornography on the internet, 900 numbers, unusual sexual demands and practices start to rule the patient's life and undermine his relationship with his wife and others. Unlike the problem of gambling, many of these patients will admit they have a problem but they are often unwilling to stop their medication.

The other common problems are shopping and eating. However, there are many types of behaviors that may occur and some of them are so odd or so exquisitely focused that it makes the interaction between drug and brain even more wondrous than we had thought. I have a patient who developed involuntary speeding when driving a car. "How fast do you go?" "I'm limited only by the car in front of me." Or the patient who

baked a cherry pie every day although neither he nor his wife liked cherry pies and didn't eat them. Or the woman who could not eat enough Braeburn apples. She gained 20 pounds eating Braeburn apples. Another patient takes up watercolor painting or knitting but does it 20 hours a day, missing sleep, ignoring all other aspects of life, peeing on herself in order not to interrupt the activity. How can anyone explain how taking a dopamine agonist would cause a compulsion to eat one type only of apples in one patient, to gamble in another, or to paint in yet another?

What unites these behaviors is their compulsive nature. The patient loses control of his/her choices. He/she can no longer decide rationally what to do. They become addicted, like a drug addict. The problem with our terminology, is that the behaviors fall into different psychiatric categories, so some of us call them "repetitive" because it is usually a single type of behavior that is repeated, or "impulse control disorder" since that is how gambling and binge eating are classified, and "dopamine dysregulation syndrome" because the behavior so closely mimics drug addiction. Punding is reserved still for the senseless repetitive simple behaviors, like endless rearranging and cataloging collections of buttons, jewelry, trimming hedges, cleaning ovens, polishing pennies, etc. which are typical also of compulsive disorders.

Treatment is unclear. Obviously we'd like to reduce or stop the medicines that contribute to the problem, but, as noted above, some patients refuse to reduce their medications. Some patients may go for DBS surgery so their medications can be reduced, although there are now reports that DBS can cause these problems, too.

The good news is that these problems occur in less than 10% of the patients who take the dopamine agonists and will always go away when the drugs are stopped. The bad news is that it isn't always easy to stop the drugs that cause the problem. ■

DELAY THE DISEASE – FUNCTIONAL FITNESS

David Zid

Getting Out of a Car

This topic brought up more discussion in our weekly exercise class than any other functional exercise plan. Getting out of a car is difficult for most with Parkinson's. The seat is low and frequently hard to slide across. Our class had an open discussion of their opinions of personal struggles with this move. Based on their thoughts and my ideas, we came up with a few tricks and corresponding exercises that might make it easier for you to get out of your car. Practice all of the following; they will help you maneuver in tight space, unfreeze after a period of sitting, and increase your flexibility and ability to rotate yourself out of the car seat. Good luck. ■

Tips

MOVEMENT BEGETS MOVEMENT TRICK

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

WINDOW TRICK

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

CORNER TRICK

This trick will help you maneuver into the tight space of a car, where frequently people become frozen. Walk to a corner of a room and stand for a minute. Take a big, rotational step and open your stance, making sure you are not crossing your legs as you step. Now walk out of the corner. Repeat 5 times, turning both directions, arms straight. Rotate from your core, do not pull with your arms. Keep the rotation in your torso, avoid bending your arms. Repeat 5–10 times.

Exercises

SEATED SIDE STEPS

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



12-INCH BOX (ADVANCED)

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

BICEP CURLS

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



PHOTO CREDIT: NANCY MARBLE

Our 14th Annual Focus on Fashion highlighted our favorite things—whether they were depicted in the fifty wonderfully creative centerpieces donated by **Build A Bear Workshop, Inc.**, in one of over 140 auction baskets, or on the runway in fashions featured by **Jillybean, Marta's, Pulse, PURE by Jen, Vie, Susan Lynn's** or **Savvi Formalwear**. As a family who “likes nice things,” **Brook & Melissa Dubman** and family served as Honorary Chairpersons and participated in this year's event.

Kent Ehrhardt, KMOV-TV meteorologist, served as Master of Ceremonies, always spontaneous, quick witted and adored by our audience! Our celebrity guests featured area radio and TV personalities including **Michelle Anselmo, Sean Conroy, Elliot Davis** from KTVI-Fox 2-TV, **Mark Schnyder and Janet Conners** (Larry's wife), representing KMOV-News 4, **Lisa Manzo** of AmerenUE, **Victoria Babu** from KTRS, **Mary Ann Carson, Dana Daniels and Ed Goodman** from KEZK, **Randy Gardner** from

News 20-TV, **Laurie Mac** of KHITS, and **Gilberto Pineda** from

These are a Few of My Favorite Things

STL-TV. Others on the runway modeling the latest fall fashions included

Sarah Denos, Amy Dubman, Jeff Garlich, Pat Garlich, Sarah Garlich, Mary Hebrank, Dan King, Matt LaMartina & Tom Mackowiak of the St. Louis APDA Board of Directors, **Veronica McDonnell, Lori Mundwiller, Rich Schindehette, Sarah Sordo, Kris Suntrup, Lisa Suntrup, and Eric Wood**. Since Washington University Medical School is a leader in Parkinson's disease research, the University was represented on the runway by **Risa Zwerling Wrighton**, wife of Chancellor Mark Wrighton; **Dr. Joel Perlmutter**, Director of the Center for Advanced Parkinson's Research at the medical school, and his wife **Monica**,

an occupational therapy instructor at the school. We welcomed several junior models and escorts to the runway this year, including siblings **Jeffrey, Joanie and Julia Garlich, Cameron Kopsky, Peyton LaMartina, Joy & Michael Shanahan, Audrey, Elizabeth and Kelly Suntrup, and Olivia Slay**. Makeup and hairstyling services were once again generously provided by **James Pearson Salon & Day Spa**.

The audience was entertained by dancers **Spiro Marko and Agnieszka Strojek-Maguire** who performed two numbers, including the Argentine tango. As many of you know, Dr. Gammon Earhart's research has documented the benefits of dance, as it can improve walking, balance, and quality of life among individuals with PD. A community-based program, which started on October 12th, will offer people with PD an opportunity to participate in tango classes twice a week for an entire year. Perhaps they will provide our entertainment next year!

Heartfelt appreciation to our sponsors, many whom have joined us every year for this fall fashion event: our **anonymous donor** who always generously gives at the diamond level, **Community Partnership at Benton Homebuilders** for a gold sponsorship level, **Slay Industries**



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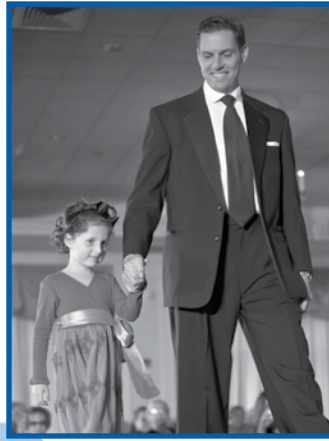


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at the silver level, **Budget Billboards, Inc. & The Delmar Gardens Family** at the bronze level, **Cooperative Home Care & Jim and Jan Otis** at the pewter level, and our wine reception sponsors **National City, now a part of PNC & Peoples National Bank.** Guests were provided with cookie favors courtesy of **Who's Your Baker?**

The St. Louis Chapter of the APDA extends their special thanks to the many wonderful volunteers, donors and guests who helped make this event a huge success. Our spectacular, eye-catching raffle items this year included a lady's white gold antique ring with brilliant cut round diamonds valued at \$3500, donated by **Scotsman Coin & Jewelry**; a lady's 18kt bangle bracelet with .22 CTW diamonds, valued at \$675, donated by **David Kodner Personal Jeweler**; a two night weekend stay at **The Ritz Carlton**, valued at \$650; a gift card valued at \$500 from **Ylang Ylang Fine Jewelry**; a silver onyx arista ring valued at \$450, donated by **Vincent's Jewelers**; and Murano glass earrings valued at \$440, donated by **Vinciguerra Jewelry.**

We have many individuals to thank who made **charitable contributions** to ensure the success of our event, including: Pat Bander, Jill Barnett, Carolyn

Bell, Joyce Berger, Joseph Burcke, Donna Cohen, Debbie & Jeff Dalin, Rebecca Daming, David Dankmyer, Walter & Connie Donius, Beverly Faber, Fox Family Foundation, Jim & Marsha Guyer, Marcia Hamilton, Susan Hearst, Greg Johnston, Lenora Walsh Kiefer, Charlene Lehn, Joe Marchbein, Jim Matush, Annetta McAninch, Mary McDaniel, Karen P. Myers, Shirley Richter, Phillip Schreiber, Mary Sinak, Doris Squires, Laurie Stafford, Karen Suroff, Anne Trower, Jack Strosnider, June Wagner, Molly Wainwright, Bob & Jennifer Walpert, Sarah Squires- Weber, Stan Wilensky, Leslie Wilson, and Eric Wood.

Needless to say, to organize and orchestrate such an event requires a team effort, and the tireless efforts of chairpersons **Lynda Wiens** (auction) and **Jill Garlich** (fashion show) and committee members: **Mary Buck, Gerry Francis, Barb Gellasch, Karen Johnson, Elaine Lindecke** (media), **Nancy Marble, Josie Mazzola, Barb Nelson, Dayle Norber, Karen Olsen, Betty Rakestraw, Dorothy Reimers** (registration), **Betty Shepley, Addie Tompkins, and Vicky Young** are to be congratulated. At the risk of leaving someone out, I wish to express my appreciation to additional support received from **Lisa Ackerman,**

Shameem Ahmed, Jim Badger, Alyce Bell, John Buck, Cherstin Byers, Liz Carney, Linda Clark, Michelle Dowell, Karl Guyer, Brian Hantsbarger, Bob Kallemeier, Linda Laramie, Tom & Grace Mackowiak, Kay Meyer, Eric Nelson, Rob Olsen, Christine Sadler, Erin Schreiber, Jack Strosnider, and Elsevier Co. employees Cheryl Abbott, Kathy Dashley, Sarah Spalding-Eichorn, Luane Guyton, Becky Harlow, Carlie Irwin, Rhonda Lemmon, Christa Robinson, Judith Schneider, Janice Strinko, Cindi Thoms, Judy Zettle. Raffle bid sheets were again provided courtesy of **Mike Corson** of **NJC Printing & Graphics**, the wonderful balloon arch entrance to the ballroom by **Barry Lasky** of **Hi Ho Helio**, and our attractive signage by **Barry Roufa** of **Fastsigns of Bridgeton.**

Please enjoy the pictures we have provided which capture a sense of our 14th Annual Focus on Fashion. Photography of the event was provided courtesy of **Cathy Hartman Photography**; see all of the event photos on Cathy's website, link provided www.stlapda.org. Other photos appearing in this article, where noted, are reprinted with the permission of Margaret Rambo/Ladue News, and Nancy Marble. ■



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HALF FULL OR HALF EMPTY?

Debbie Guyer, Executive Director, St. Louis APDA

I was scanning the crowd, trying to assess approximately how many were in attendance at the PEP meeting, when suddenly I spotted someone out of the corner of my eye. It sure looked like her, but this person was sitting straight as a poker and not slouched over in a wheelchair. I continued to count, frequently glancing in the direction of where she was seated. After the program, I was in back of the auditorium speaking with a volunteer, when my attention was drawn once again to this person, now walking down the aisle, hand in hand with a nice looking male companion. She had a broad smile across her face and she was radiant.

As she approached, I spoke her name and expressed my surprise at how terrific she looked, and my disbelief as she was walking practically unassisted; how intelligible her speech sounded, and how she didn't even resemble the person who I last saw in the clinic, hunched over in a wheelchair, barely audible, and with a

face depicting little expression. She had been "beaten" down, hopes dashed, and unfortunately institutionalized due to a change in her home situation, and I walked away from this chance encounter in the clinic feeling so discouraged and helpless.

So, what had changed? The physical difference was almost unbelievable. The emotional outlook- judging from the smile that never left her face, I think it would be safe to say that her despair had turned to unbridled hope. Being happy has a way of making us feel hopeful. When you have something to look forward to, something to pin your hopes to, whether it is a special visitor, a favorite meal, celebrating a holiday with loved ones, our troubles take a second seat and seem much smaller and easier to handle. I don't want to appear to be Pollyanna and tell you that the things you fear about having a progressive disease with no cure (yet) are not real-but a change in perspective, from feeling

down to being up, from feeling hopeless to being hopeful, through shared compassion and sensitivity...it's mind over matter and just may make a difference. It did for her! Enjoy this holiday season-there really is so much to be thankful for. ■

RESEARCH STUDY

The Parkinson Study Group is conducting a research study of Dynacirc CR (Isradipine), an FDA-approved hypertension medication, as a treatment for patients with Parkinson's Disease (PD).

If you are interested please contact Mary Pecoraro at Washington University, **314-747-7017**.

For a full description of the study, including criteria for participation, please visit online: <http://www.clinicaltrials.gov/ct2/show/NCT00909545>.