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American Parkinson Disease Association

APDA Greater St. Louis Chapter

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OUR MISSION

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

The Ice Bucket Challenge

Minus the Ice and the Bucket

By Debbie Guyer, MA, Executive Director

When politicians discuss how to manage the budget deficit, do you ever wonder what would happen if every American contributed just \$1 or more? The deficit would be significantly lower than it is today and might quite possibly not exist at all. And so one morning, I posed this question to my staff. What if everyone who received the LiNK newsletter, whether they are an individual who has Parkinson disease, or a family member, or a care provider, or a professional, each donated what they could, within their means, to the Greater St. Louis American Parkinson Disease Association (APDA) – \$1, \$10, \$100, \$1,000 – times 9,500 individual mailing addresses – couldn't we create a virtual fundraiser? It would be an opportunity for everyone who is touched by or touches this disease to make a difference and demonstrate their commitment and "ownership" by making a contribution to further our mission of *easing the burden* of living well with Parkinson disease while researchers continue their efforts to *find causes and a cure!*

With an audience of 9,500 households connected to the Greater St. Louis

American Parkinson Disease Association, we have an exciting opportunity. If 9,500 contribute simply what they are able, that would make an enormous difference by ensuring that people maintaining strength and balance through our wonderful weekly exercise classes, or engaging in our monthly support groups, or attending an educational meeting, or becoming better educated by reading the LiNK newsletter can enjoy these programs and services any time they need them.

We are proud to be setting the standard and raising the bar for other chapters around the country. I am proposing that we consider doing our own Greater St. Louis Chapter ice bucket challenge, but minus the ice and the bucket. Instead of the freeze of the ice, together we can generate the warmth of community by ensuring a family in need can always access programs, support and education through APDA. What has touched you, a loved one or a friend? Five dollars allows two LiNK newsletters to reach individuals looking for opportunities for programs and support. If a support group provided understanding, a donation of \$25 would provide funding to rent a space for

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Disclaimer: The information and reference material contained herein concerning research being done in the field of Parkinson disease and answers to readers' questions are solely for the information of the reader. It should not be used for treatment purposes, rather for discussion with the patient's own physician.

APDA Advanced Parkinson Research Center at Washington University in St. Louis-Research Update

By Joel S. Perlmutter, MD, Department of Neurology, Head, Movement Disorders Section,
Washington University School of Medicine

This year we have made substantial progress in our Parkinson disease research efforts. Again much of this work has been supported by the Greater St. Louis Chapter of the APDA and the APDA Advanced Research Center at Washington University. Of course, we also thank all of the volunteer participants in our research studies – without whom none of this work would have been possible.

I want to give an update on our research fellows who have completed their neurology residency and are now taking additional training in Movement Disorders with a focus on Parkinson disease. Dr. B. Maiti has started his second year of fellowship training with us and has been focusing on our studies of thinking problems that occur in PD. Our new fellow, Dr. Albert (Gus) Davis, is working in Dr. David Holtzman's lab concentrating on various aspects of alpha-synuclein. Dr. Holtzman, Dean of Neurology, investigates the function of abnormal brain proteins which include alpha-synuclein (the abnormal protein that occurs in the brains of people with PD). Once again, we have received a substantial gift from Mrs. Jo Oertli that continues to support these fellowship opportunities.

A major area of research has focused on the changes in the brain that lead to cognitive difficulties in people with PD.

We have previously found that everyone with PD and thinking problems has abnormal deposits of the protein alpha-synuclein in higher parts of the brain called the cortex. This past year, we found that spinal fluid contents of alpha-synuclein correlate with the amount of another protein called A-beta. A-beta is typically one of two abnormal proteins that accumulates in the brains of people with Alzheimer disease and in about 60% of people with PD and dementia. This relationship does not occur in people without PD and is important since this, along with

our spinal fluid findings, is more evidence that people with PD only uncommonly have brain changes typical of Alzheimer disease. That is to say, PD and Alzheimer disease have different types of brain changes.

Another study that we published in the journal *Neurology* showed that the spinal fluid levels of alpha-synuclein in people with PD also correlated with the strength of brain networks that we can measure with a special type of MRI scan known as a resting state study. These particular studies are done with someone lying quietly in the MRI scanner.



This was the first evidence that the alpha-synuclein protein actually relates to specific brain functions. We also published a paper describing the cognitive reserve or amount of damage that must occur to the brain prior to development of difficulties with thinking in people with PD. In this particular study, we found that

those with less than 16 years of education had more trouble with thinking if they had PET measures of increased A-beta in the brain. Thus, these findings suggest that more education in people with PD protects against the clinical effects of A-beta deposits in the brain. Perhaps most interesting is the recent paper published showing that several different brain chemical messengers are substantially decreased in various brain regions. Classically, the focus has been on the loss of dopamine, but these new findings indicate major reductions in serotonin and norepinephrine. We found

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FOG-Freezing of Gait

By Ryan Duncan, PT, DPT and Beth Crowner, PT, DPT, NCS, MPPA; Washington University School of Medicine, Program in Physical Therapy

Have you ever tried to take a step and felt like your foot was glued to the floor? This phenomenon is referred to as freezing of gait (FOG), and it affects approximately 20-60% of people with Parkinson disease (PD). The underlying causes of FOG are poorly understood. Formally defined, FOG is the transient inability to produce an effective stepping motion. Situations frequently associated with FOG are turning, walking through doorways, walking while changing surfaces (e.g. carpet to hardwood floor), or when walking in narrow or crowded spaces. Because the body continues to move while the feet stay fixed to the floor, FOG is one of the most significant risk factors for falling in people with PD. While FOG is often frustrating and may lead to fear of falling, there are specific movement strategies that may help reduce FOG severity.

The most studied intervention targeted at reducing FOG is the use of cueing. Cueing takes many forms: 1) auditory, 2) visual, and 3) attentional.

Auditory cueing often involves the use of a metronome or rhythmic music. The person with FOG is instructed to step at a certain beat. The prevailing thought is that this helps restore a more normal rhythm needed for walking, which is often lost in people with PD. Visual cues are used in several different ways. Taped lines on the ground, cracks in the sidewalk, or your spouse's foot to step over to get started are examples of visual cues. Some canes or walkers can have a laser pointer attached to them, which produces a line on the floor that acts as the target to step over. Attentional cues, perhaps the most practical type of

cues, require the person with FOG to pay attention to how they move. For those with PD, walking typically becomes less of an automatic behavior. This means that an individual with PD may benefit from paying attention to their stride to help establish an improved walking pattern. When a caregiver or friend tells one with PD to "take big steps" or "heel-toe," this is using attentional cues. The person with PD focuses their thinking on the length of their stride or hitting with their heel first when taking a step to help to facilitate an effective gait pattern.

The research on all three types of cues shows positive effects of each. When used,

stressed or trying to force through a freeze will often prolong the freeze, making it more difficult to move.

If you experience FOG, shuffling, or difficulty walking, a physical therapist can be a useful resource in helping you to understand which type of cue might benefit you most. A physical therapist with experience in treating people with PD is trained to determine which cue provides the most benefit and how to optimize that specific cue to improve walking and reduce FOG. People with severe FOG may benefit from using an assistive device like a walker, and a physical therapist can help determine which device is best

for the person with PD. Because some individuals with FOG also have difficulty with standing balance, a physical therapist can also provide exercises to improve the factors that cause instability with walking.

In summary, FOG is a common and frustrating problem for some people with PD. There are strategies that are effective in

improving movement and reducing FOG. A physical therapist with experience in treating people with PD will work with you to determine how to best improve your walking and decrease FOG. ■

Drs. Duncan and Crowner are physical therapists with extensive experience in treating individuals with Parkinson disease and other movement disorders. They regularly see patients at the Washington University Physical Therapy Clinics. A referral from your neurologist or primary care physician is needed to initiate treatment. For further information, call 314.286.1940.



the cues result in improved walking speed and stride length. However, when they are taken away or are not used, the gait pattern returns to baseline. This suggests that these cues, whichever is preferred, must be used regularly to maintain the improvements in walking. To date, there is no research to show that one type of cueing is superior to another. Oftentimes the response to each cue varies from individual to individual.

Because physical or emotional stress tends to increase symptoms in people with PD, it is very important to avoid getting upset during a freezing event or trying to "push your way through" a freezing event. Being

Medicare Part D Open Enrollment:

Do Your Homework (Even If You Already Have a Part D Plan!)

By Stacey K. Barton, MSW, LCSW; Department of Neurology, Movement Disorders Center, Washington University School of Medicine

Medicare Part D is the prescription drug benefit associated with traditional Medicare. Despite being in effect since 2006, many people remain confused about how to make the most of the benefit. This article will focus only on Medicare Part D with traditional Medicare, not drug coverage obtained through a Medicare Advantage Plan (Part C).

The Basics Part D was enacted to provide financial relief to Medicare recipients from the high cost of prescription medications. Coverage for both brand name and generic drugs is provided by private companies offering prescription drug plans (PDPs) and covers prescriptions obtained from retail and mail order pharmacies. Each PDP will have its own list of covered medications (formulary) and within the formulary, drugs will be assigned to different tiers. Higher tier drugs cost more.

Participation in Part D is open to everyone with Medicare, but it is not free. Medicare recipients can enroll in Part D when they first become eligible for Medicare. Indeed, most people should enroll upon initial eligibility, otherwise they may incur a permanent penalty of 1% of the national monthly premium average times the number of months a person failed to enroll. Exceptions to this are those who can prove they have other coverage that is equivalent or better (such as through employment or retiree medical benefits) or those who have low income and qualify for the Extra Help Program (more on that in a minute). For those who didn't sign up when first eligible or who wish to change plans, open enrollment is annually from October 15 to December 7 for coverage beginning on January 1 of the following year.

Costs Part D costs come in several forms: the monthly premium, annual deductible, copayments/coinsurance and costs in the coverage gap. The monthly premium varies by plan but the 2016 annual average is expected to be \$32.50 per month. Not all plans charge a deductible, but for those that do

the 2016 maximum annual deductible is \$360. Copayment and coinsurance costs vary by drug tier. The coverage gap, commonly referred to as the “donut hole,” is the period of time when the insured person reaches the Medicare



Part D plan's initial coverage limit. It ends when the person has spent enough out of pocket to meet the out-of-pocket threshold and enters the catastrophic coverage period, which would stay in place for the rest of the year. The Affordable Care Act included a provision for the donut hole to slowly close. In 2016, while in the donut hole, Part D enrollees will receive a 55% discount on the total cost of their brand name drugs. 50% of this discount is paid by the drug manufacturer and 5% is paid by the PDP. The good news is that 95% of the cost of the drug (the 45% you paid and the 50% paid by the drug manufacturer) will be “applied” towards your out-of-pocket costs which means you will exit the donut hole much faster. For generic drugs you will pay up to 58% of the cost. Nothing additional is applied toward your out-of-pocket costs.

For example: You are in the donut hole and purchase brand-name medication

“B” (retail cost \$100) and generic medication “G” (retail cost \$50). These two medications will cost you \$74 (\$45 for “B” and \$29 for “G” after the discount), but \$124 (\$45 plus \$50 for “B” and \$29 for “G”) will be applied towards your out-of-pocket maximum.

Once you have exited the donut hole, you enter catastrophic coverage until the end of the calendar year. During that time, you pay only 5% of the cost of the drug (or \$2.95 for generics or preferred drugs or \$7.40 for all other drugs, whichever is higher).

Making the Most of Your Benefit

Now that you understand the basics of costs, there are steps you can take to maximize your benefit.

The most important thing you can do is to reconsider your PDP every year, even if you are satisfied with your current coverage! The reason for this is because the “best” plan for you may have changed. If your medications changed even a little over the year, another PDP could be cheaper, and also PDPs themselves change coverage and costs a lot from year to year (and usually do!). For example, one year my mom's plan costs quadrupled even though she only took two very inexpensive generic medications. We found a new plan that was less expensive and switched her plan (even though the current one was the cheapest the prior year!). Remember also that, with only rare exceptions, you can only change your PDP once per year, during open enrollment, so it is important to make changes while you can.

To evaluate the PDPs from which you can choose, start by visiting <https://www.medicare.gov/find-a-plan/questions/home.aspx>. Enter your ZIP code and

then choose the correct answer to “How do you get your Medicare coverage?” If you have traditional Medicare, which is what this article is aimed at, you will select “Original Medicare.” You can choose “I don’t know” to the next question unless you are certain you benefit from a program on the list. Click “Continue to Plan Results.” Next, enter your medications, including the accurate dose and number of tablets (this can make a big difference!). Once that is completed, you will select your preferred pharmacy or pharmacies on the next screen. This is also important because some plans provide better coverage at some pharmacies so you will want to make your decision based upon the pharmacy you prefer. If you are open to considering other nearby pharmacies or mail order, that may allow you to reduce costs.

On the next screen, it is important to choose “Prescription Drug Plans (with Original Medicare).” The only reason you would not select this option is if you are looking at the option of giving up traditional Medicare and enrolling in a managed care plan instead. This choice has big implications outside of medication costs and is well beyond the scope of this article.

When you continue to plan results, you will see the PDP choices available in your area. The default first result will be the lowest annual drug cost at your preferred retail pharmacy. You may notice that your costs can vary by thousands of dollars per year from the cheapest PDP to the most expensive!

A Few Tips

- For some people, the cheapest plan over the course of the year may have a deductible. Some people would rather avoid the deductible to keep their monthly costs flatter even if it costs a bit more annually. If that is true for you, pay attention to whether the plan you are looking at lists a deductible.
- Many people only compare the monthly premium in making their choice. This is a mistake. Plans with low monthly premiums may make up the costs elsewhere by having deductibles, drug restrictions, or

placing your medications in higher tiers.

- Consider mail order. To check for the lowest cost mail order plan, change the “Sort Results By” at the top to select the mail order option. You can also see that you have other sorting options there as well.
- By clicking on the red box in front of the PDP name and then clicking “Compare Plans,” you can select up to three PDPs to compare side by side. Note that they may not appear on the next screen in the same order they were on previously!
- Another helpful feature of clicking the “Compare Plans” button is that you can see your expected monthly drug costs (including the monthly premium). You can also see when you are expected to hit

Standard Medicare Part D Benefit, 2016

Deductible - \$360 - Dependent on plan

Initial Coverage Period - \$3,310

You pay 25%, PDP pays 75%

Coverage Gap – You pay total cost of drugs, minus discount.

Catastrophic Coverage - >\$7,062.50

You pay 5%, PDP/Medicare pays 95%

the coverage gap, if at all. This is very important so you can plan ahead! Every year we get calls from patients who are surprised when they hit the coverage gap and have no plan to pay for their medications. There are very few options for help in the coverage gap beyond the provisions already in place by the Affordable Care Act.

- If you are switching plans or signing up for the first time, you can click the “Enroll” button on the right. If you are keeping your same plan, it is not necessary to re-enroll. If you are switching plans for 2016, enrolling in a new one will automatically trigger the old plan to stop at the end of 2015. No additional work is necessary on your part to cancel your current plan.

Getting Help with Drug Costs People with lower resources may also be eligible for a special program called the Low Income Subsidy or “Extra Help” program. As of the time of this writing, the 2016 income and asset limits are not posted but they are likely to be similar to 2015.

In 2015, the income limit for individuals was \$17,655 per year and for married couples it was \$23,895 per year. Resource limits were \$13,640 for a single person and \$27,250 for a married couple. Resource limits apply to money in the bank, stocks and bonds but do not include the home, one car, burial plot, up to \$1,500 set aside for burial expenses, and household items. Even if you are over these income or resource limits a bit, try applying anyway; many people have been successful.

People who qualify for Extra Help receive assistance paying for their deductible, copayments and costs in the coverage gap. Depending on the level of Extra Help, you may still incur a small copayment, but the maximum copayments in 2016 are \$2.95 for generics or preferred drugs and \$7.40 for all other drugs.

If you aren’t sure if you qualify for Extra Help, apply anyway! It is a quick online application and can save you thousands of dollars. To apply, visit <https://secure.ssa.gov/i1020/start> and follow the instructions.

Other ways to lower your costs may be to switch to generics when possible, use a mail order pharmacy, talk to your doctor about other drug options that may be on a lower tier, or see if your state has a Pharmacy Assistance Program. In Missouri the Pharmacy Assistance Program is called MORx and information is available here: <http://www.morx.mo.gov/>.

These are difficult economic times, but there are things you as an informed consumer can do to maximize your benefits and limit out-of-pocket costs. If you need assistance with navigating your Part D options, APDA may be able to provide a referral for social work assistance. ■

Sewing THE SEEDS OF Optimism

Over 300 people joined us in the Versailles Ballroom at the Sheraton Westport Chalet on October 12, 2015, to support the APDA annual auction, luncheon, and fashion show. The afternoon began with our silent auction, in which attendees were able to shop for wonderful baskets, restaurant gift certificates, and one-of-a-kind items. Jennifer Blome, Director of Humane Education at the Animal Protective Association & former anchor of Today in St. Louis, joined Kelly Jackson of KSDK-TV & KTRS-Radio as co-emcees, and they kept the commentary running and amusing. Dr. Joel Perlmutter spoke enthusiastically of the progress being made for people with Parkinson's and the promising research being conducted not only at Washington University School of Medicine but around the world. He shared exciting new findings resulting from brain tissue examinations, including several different brain chemical messengers, serotonin and norepinephrine, which are reduced in various regions of the brain. This is a particularly important finding since it suggests other drug targets beyond the usual replacement of dopamine.

Scientists continue to make progress in development of a medication, carboxyfullerene, which has potential to slow damage to dopamine-producing cells, resulting in a slowing of PD progression. Debbie Guyer recognized the many sponsors and volunteers for their time and effort in putting together the auction and fashion show. A small segment of a recent TED lecture with Robin Morgan was played for the audience, with Ms. Morgan reciting a poem she has written called "No Signs of Struggle." The audience was moved by the author's rhythm and music of language; with the power of metaphor and imagery Ms. Morgan captured the essence of how "growing small requires enormity of will." Honorary Co-Chair Terri Brennan spoke on behalf of herself

20th Annual Auction, Luncheon, & Fashion Show

and her husband, Gerry, about the impact that the APDA has had on their family and her realization of the importance of daily exercise in slowing down the progression of this intruder. She shared a very common feeling of relief at having finally received an accurate diagnosis after years of trying to find the answers to her emerging difficulties.

The event was a huge success, raising almost \$90,000 to support our mission, and we could not have done it without the help of our tireless volunteers. Lynda Wiens, Auction Chairperson, was the woman behind the creative and beautiful baskets and auction room. Congratulations and deep appreciation go to our Fashion Show Committee members who went from shop to shop, restaurant to restaurant, collecting items and gift cards for the silent auction. Fashion Show Chairpersons Joanie Goldstein, Sherrie Rieves and Kathy Wunderlich gathered a lovely group of returning and first-time models and brought fresh ideas and fun to the runway. The guests were treated to fashions by new and returning local boutiques including Camille La Vie, Mister Guy- The Men's Store, Mister Guy- The Women's Store, Paperdolls, Savvi Formalwear and Vie. A round of applause goes to our 26 models and to the boutique owners and designers who selected fashions off their racks and outfitted our lovely models.



Chris Vinyard & Fran Zamler



Amy Dubman

The Tremble Clefs, a singing group comprised of 35-40 people with Parkinson disease, sang two songs and provided entertainment for the event. The Tremble Clefs choir is led by music therapist extraordinaire, Linda McNair, MT-BC, and accompanied by Anna DiVesta. Our guests each enjoyed receiving plantable seed paper dresses from Cast Paper Art, which is owned by the Tremble Clefs' own Steve Deines. Steve also spoke to the crowd to talk about how Parkinson's had changed his life and career as an opera singer, as well as treating everyone to a short song with lyrics written by the choir to the song "Imagine."

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A heartfelt thanks to all the volunteers, bankers, and runners who made sure the event progressed smoothly. For many years now, volunteers from Elsevier have come to help with the auction as their day of giving back to the community. We also had many APDA volunteers who help with our programs, assisting the staff before, during, and after the event. Thanks to all who attended the event – we hope you had a great time. For a complete viewing of all the photography taken by and courtesy of Lori Gambill, and video production by Larry Balsamo of Video Views, visit www.stlapda.org.



Fran Zamler

Wine Reception (\$500)

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- Kena Blanton
- Ann Cook
- Tricia Creel
- Debbie Dalin
- Lori Gambill
- Brian Hantsbarger
- Ellie Hatrich
- Barb Koch
- Marty Lemley
- Benjy Levin
- Joyce Levin
- Craig Miller
- Dayle Norber
- Erin Schreiber
- Marilyn Warren

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- Tara Faller
- Becky Harlow
- Lisa Huddleston
- Celeste Schneiderer
- Julie Swyers
- Nick Wolf
- Judy Zettle

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- Jamie Archer
- Melissa Bohlmann
- Rebecca Bruchhauser Farris
- Katie Byrum
- Leslie Byrum
- Louis Christoffersen

A Thanksgiving Wish

By Debbie Guyer, MA, Executive Director

Few people are grateful to be diagnosed with Parkinson disease (PD), or the symptoms it brings and the side effects of the medication. As we approach Thanksgiving, however, it is important to take stock of what is good in your life.

Perhaps you've met some of the best friends you've ever had through your support group. Maybe dance has helped improve your movement and Tai Chi your balance.

And, of course, there are the blessings of family and friends.

Here at the Parkinson Association, we are thankful to be able to answer a question for that caller or to find the perfect support group for the newly diagnosed person. We feel grateful for the opportunity to provide quality education programs and supportive family services to those living with PD every day. Mostly, we are thankful for YOU and your support throughout the year.

A colleague of mine, Stacy Tew-Lovasz, President/CEO of the local Alzheimer Association, emailed this message of thanks to their members years ago. I would like to share her thoughts, as it captures what we'd like to say to you as well.



Thank you for raising your voice.

Thank you for creating awareness.

Thank you for your financial support.

Thank you for your time.

Thank you for influencing change.

Thank you for advancing research through donations or clinical trials.

Thank you to those who provide care, who we honor especially this month.

Thank you to those who fight and don't let this disease define them.

This is a time for reflection and thanksgiving, but the words "thank you" cannot fully express how grateful we truly are. In addition to our words, please let our unyielding actions of providing care and support and our relentless quest to advance research serve as a sincere and wholehearted "thank you."

Here's to a holiday season full of blessings. ■

Over-The-Counter Medications – Use with Caution! (Part 1)

By Morvarid Karimi, MD, Department of Neurology, Movement Disorders Section, Washington University School of Medicine

Cold-related supplements As we approach the cold and flu season, let us review a few basic tips. Most upper respiratory illnesses are due to viral infections. This means that antibiotics do not shorten the course of the disease. Taking antibiotics, when not indicated, can not only harm you by killing off the good bacteria in your gut but also increase the risk of bacteria becoming resistant to these antibiotics in our community. The first crucial step is prevention. Please make sure you receive your yearly flu shot and that you are up to date on the pneumonia vaccination. Wash your hands frequently and teach children in particular around you to cover their mouths with the bend of elbow when coughing or sneezing. Despite all precautions, when you catch an upper respiratory illness make sure that you drink plenty of water. Hydration helps you feel better and makes it easier to cough up mucous and clear your airways. If you develop a high fever and severe body ache, please see your primary care physician as soon as possible as you might have influenza which can affect you even if you have had a flu shot. The reason for the urgency is that your doctor can prescribe a special antiviral medication for you that is effective

only if taken within the first two days of the illness. Although there is no cure available for most upper respiratory illnesses, you can take over-the-counter medications that help you feel better. Please avoid "cocktails;" these are combinations of two or more over-the-counter medications marketed under a promising name. Instead look for medications that have **only one** active ingredient and use it to address a specific complaint.

Antihistamines: They help with runny nose, sneezing, itchy or watery eyes, or allergic reactions like hives. Examples are diphenhydramine (Benadryl), chlorpheniramine (Chlor-Trimeton), loratadine (Claritin), and cetirizine (Zyrtec). Diphenhydramine is the most effective one; however, it results in the greatest risk of drowsiness and confusion, especially if there is any cognitive decline or tendency toward hallucinations. That is why we usually ask our PD patients to avoid it and use loratadine or cetirizine instead. Certainly it is best to take these at bedtime, when sleepiness is not a problem.

article to be continued in the February 2016 issue

TRIBUTES & DONATIONS 07/01/2015-09/30/2015

Tributes are a thoughtful way of expressing sympathy, giving thanks, celebrating special occasions such as birthdays, anniversaries, holidays; or honoring the memory of a loved one or friend while expressing your commitment to the Greater St. Louis Chapter of the American Parkinson Disease Association. An acknowledgement including your name (but not the amount) will be sent to the person honored or to a relative in case of memorial, and the donor will receive a prompt thank you card/letter which can be used when filing your tax return.

HONORING

Mr. and Mrs. Morton Baron on their anniversary

Rita Eiseman

Shirleen Baris on a speedy recovery

Sharna Kohner

Steve Bilyeu

Wayman & Imogene Bilyeu

Barbara & David Boxer on their special anniversary

Rita Eiseman
Penny Kodner

Ben & Charlie Cohen on their 5th birthday

Billy & Terri Taylor

Barbara Cupples on her special birthday

Pam & Jerry Brown

Roz Gad on her 85th birthday

Billy & Terri Taylor

Bill Gerth III

Erika & Bill Gerth

Mr. Al Gruben on a speedy recovery

Mr. & Mrs. Jerry & Pam Brown

Mrs. Nancy Kalishman on her birthday

Rita Eiseman

Mark Kodner

Virginia Haigler

Louis Loebner on her special birthday

Rita Eiseman

Josephine & John Mazzola on their 50th wedding anniversary

Terry & Sandra Allen
Sue & Kelly Price

Andy & Alice Nutis on their 50th wedding anniversary

Mark & Laurel Capron
Mary Collins
Mike & Linda Ford
Sherry Silver
David & Mary Thien

Mrs. Bonnie Perlman on her special birthday

Mr. & Mrs. Jerry & Pam Brown

Dr. Joel Perlmutter

David & Barbara Furman

Harold Rosner on his 80th birthday

Paul Stumpe

Ruth & Sylvan Sandler on their special anniversary

Ms. Gertrude Hulbert

Kathryn & Bernard Schubert on their 70th wedding anniversary

Eva Sketoe

Anita Selle

Howard Selle

Jack Strosnider on his 90th birthday

Jean Stemmler

Linda Wallace on her granddaughter Emma's Bat Mitzvah

Sharna Kodner

Vernon L. Wein on the occasion of his birthday

Sharon Wein

Bob & Lynda Wiens on their 49th wedding anniversary

Karl & Debbie Guyer

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**Pictures for Parkinson's**

Gail and Larry Glenn hosted an evening Optimism event, "Pictures for Parkinson's," at their home in late August. It featured prints of photos that Larry has taken over the years and during a recent excursion to Cuba. Pictures for Parkinson's was a resounding success with \$6,323 raised. The overwhelming support from Gail & Larry Glenn and their community of family and friends continues to be an inspiration. Earlier this year, Team Glenn raised over \$12,000 for the APDA at the GO! St. Louis Walk/Run and to date have raised more than \$18,000 for the Parkinson community. What an incredible force they are! We can't wait to see what they do in 2016.

Casual for a Cause

Employees at the KBM Group Health Services in Chesterfield participated in a quarter-long campaign to raise funds for Parkinson disease, in honor of the owner's father-in-law who is battling the disease. Donations were collected for a period of 13 weeks, as employees purchased the privilege of dressing down on casual Fridays by making a donation to support the Parkinson community. Over \$2,000 was raised during this quarter, proving that dressing down never felt so good (both physically and emotionally)! KBM Group raised almost \$2,500 for the Greater

St. Louis Parkinson community during the third quarter of 2014 as well. We look forward to this becoming an annual tradition. Thanks so much for your support again this year.

Journey for Charity Tractor Cruise

Bob Weber participated again this year in the Knights of Columbus Journey for Charity Tractor Cruise. Bob's wife, Carol, facilitates our Washington, MO, Support Group. Bob collected \$855 which is more than the \$843 collected in 2014. He is approaching the \$1,700 mile marker (for the two years) during this 30-mile tractor cruise, which begins in St. Claire, MO, and ends in Washington, MO. This is the ninth year for such an event and Bob's second year participating. Each tractor owner chooses a favorite charity, and Bob chose to collect for the American Parkinson Disease Association, and we're awfully glad he did! CONGRATULATIONS on a job well done! We hope to see Bob back in the tractor cruise next year, raising more money to further our mission of easing the burden and finding a cure.

The generous support from the friends and family of Gail & Larry, employees of KBM Group, Bob Weber, and the many other Optimism events across the Greater St. Louis area help us continue in our mission to enhance the quality of life for people with Parkinson disease and provide funding for ongoing Parkinson research

It is very impressive that these three Optimism Events held since our August newsletter have generated \$9,237. What Optimism Event can you or your family sponsor?

The Ice Bucket Challenge Minus the Ice and the Bucket *continued from page 1*

our meetings each month. If an exercise class helped maintain mobility and independence, \$50 would provide 10 weeks of exercise. If education and knowledge about research empowered you or brought you hope, \$75 provides a special speaker. Bringing these gifts to our community – your community – is a gift that will bring others – and YOU – great warmth this time of year and no ice and no bucket required!

Big things often have small beginnings. Together, we learn. Together, we discover. Together, we create. Together, we heal.

Together, we innovate. Together, we lead. Please consider making a contribution which will help us maintain critical programs and expand new ones to meet the needs of our growing Parkinson community. It will enable us to support the research being conducted to find causes and ultimately a cure for Parkinson disease. The overriding goal is to make Parkinson's no one's disease, and that can and will be accomplished with your help.

Every one of us can make a difference, together! ■

APDA Advanced Parkinson Research Center at Washington University in St. Louis-Research Update *continued from page 2*

these changes upon examination of brain tissue from those that donated their brains after death. This is a particularly important finding since it suggests other drug targets beyond the usual replacement of dopamine. These studies have been done with a large team of investigators including Drs. Meghan Campbell, Chandana Buddhala, Nigel Cairns, Paul Kotzbauer, Erin Foster Voegtli, OTD, Johanna Hartlein, NP, and others. These important studies have continued to be supported by the Chapter and the APDA Advanced Research Center. We still need volunteers to participate in this study – we now have 274 but still need another 50 participants.

We also continue to make progress in development and validation of neuroimaging measures of PD severity. Such measures are absolutely critical for us to determine whether any new treatment can slow disease progression. Much of our research targeted measures of the nerve cells that make dopamine, but we have now extended these studies to other brain chemical messengers. For example, we are now able to measure acetylcholine, another chemical messenger system in the brain. This new radiotracer that we can measure with PET scanning has been developed by Dr. Will Tu and his team, and we have begun initial studies in humans with this. We have already started making these measurements with PET in people. In addition, we have completed a series of studies using a new PET radiotracer that measures another part of the dopamine system called PDE10A. PDE10A is a part of the dopamine system that helps

to translate dopamine effects on a nerve cell. In effect, PDE10A helps transmit nerve messages transmitted by dopamine, thereby controlling this signaling system in the brain. There are many actions related to PD that may relate to changes in this PDE10A system, and we can now begin to investigate these systems. This work has been done by Dr. Morvarid Karimi, Dr. Tu, Dr. Xu, and others. Again, much of the preliminary work necessary to obtain these data were supported by the APDA Greater St. Louis Chapter.

Finally, we continue to make progress in development of a medication that has potential to slow PD progression. This work has been done in collaboration with Dr. Laura Dugan, now at Vanderbilt. She discovered a new drug called carboxyfullerene, and we have completed a 10-year study to determine its effects in an animal model of PD. This study demonstrates that carboxyfullerene has potential to slow damage to nigrostriatal neurons – those are the dopamine-producing nerve cells that degenerate in PD. We published this last year in *Annals of Neurology*. Prior to starting studies in humans, I wanted to develop a method to measure how carboxyfullerene targets specific brain systems. This is important to help determine proper dosing in humans – that would make a research study in humans much stronger and more likely to succeed. We are about to begin these studies to identify such a measure. These studies have included Drs. Tian, Karimi, Norris, Dugan, Mink, Tabbal, and Moerlein. Again, this work was initially supported by the Chapter, then by two

separate NIH grants, and now donations are helping to keep this important work moving forward.

These are just a few of the studies done at the Advanced Research Center. Dr. Racette and his team continue to make outstanding progress in the risk that environmental exposures play in the development of parkinsonism as well as describing some of the disparities in providing care to under-represented ethnic groups. Dr. Gammon Earhart continues to make great progress in the effects of various exercise and rehabilitation strategies in improving quality of life and reducing morbidity of PD.

None of this research would be possible without our volunteers and many of their care partners. The Chapter support remains key for us to make this progress. Individual donations and funds raised at events help the Chapter support a grant provided to the Advanced Center for Parkinson Research at Washington University in the amount of \$100,000 annually. We need to work together to bring better treatments to people and families affected by PD. Debbie Guyer continues to keep us on track and has been particularly helpful in coordinating support for our research efforts and the care of people and families affected by PD. Susan Donovan has been an amazing administrative director of our APDA Advanced Research Center. Together, these two have managed to be incredibly effective members of the team. ■



Missouri Support Group Calendar

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, check our website, www.stlapda.org, or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold**.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	2:00 PM	Gayle Truesdell	636.923.2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street, Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck	636.532.6504
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard, PhD	636.778.3377
Columbia*	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton	573.356.6036 573.434.4569
Creve Coeur	St. Louis	Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl. CLI Rm. 419	3rd Tuesday	6:30 PM	Joe Vernon	314.614.0182
Creve Coeur	St. Louis	Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl., CLI Rm. 419	3rd Tuesday	6:30 PM	Doug Schroeder	314.306.4516
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Laura Sobba	636.931.7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314.869.5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Byers United Methodist Church 1730 S. Byers, Gymnasium	Every Monday	3:00 PM	Nancy Dunaway	417.623.5560
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816.861.4700 x56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW Patty Waller	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 & David Dalton	573.356.6036 573.434.4569
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	573.201.7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314.846.5919
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	2nd Thursday	2:00 PM	Valerie Givens, RN	417.820.3157



continued from previous page

Missouri Support Group Calendar

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636.926.3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573.543.2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283 660.485.6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314.713.4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, MSG	314.373.7036
Webster Groves	St. Louis	Laclede Groves 723 S. Laclede Station Rd.	3rd Wednesday	3:00 PM	Dina Spies	314.446.2594



Illinois Support Group Calendar

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, check our website, www.stlapda.org, or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last LiNK appears in **bold**.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Alton	Madison	Senior Services Plus 2603 N. Rodgers Ave.	2nd Tuesday	9:30 AM	Kim Campbell	618.465.3298 x146
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Jodi Gardner, MSW, LCSW	618.234.4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, MD	618.549.7507
Centralia	Washington	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Dennis Krupp Betty Evans Helena Quaid	618.545.6597 618.533.0224 618.493.6064
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Road	Every Monday	10:00 AM	Charles Rohn Chuck Arbuckle	217.549.6167 217.586.3100
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Nancy Goodson Rich Rogier	618.670.7707 618.288.3297
Greenville	Bond	Bond County Sr. Center 1001 E. Harris Ave.	4th Monday	10:30 AM	Anna Oestreich	618.664.1465
Greenville	Bond	Bond County Sr. Center Baumberger Comm. Rm. CAREGIVERS ONLY	4th Friday	1:00 PM	Anna Oestreich	618.664.1465
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut—Meeting Room 2	1st Wednesday March–December	6:00 PM	Karen Ladd	217.377.4973
Mattoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217.268.4428
McLeansboro	Hamilton	Heritage Woods – Fox Meadows 605 S. Marshall Ave., Dining Room	1st Wednesday	1:00 PM	Paula K. Mason	618.643.3868
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	3rd Sunday Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.483.4300



Exercise Classes

The APDA now offers 14 exercise classes that meet weekly. Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our patient services funding comes from donations and is limited, so we encourage those who wish to attend multiple classes to make a \$5 per week donation. This minimal donation helps us defray the cost of the classes which run around \$10 per person to cover the instructors' salaries, room rentals, and equipment. This donation request is on an honor system, and we don't turn anyone away from attending as many classes as they choose. To make a donation for exercise classes, use the blue envelope in your newsletter and note that it is for exercise class. Many people choose to pay quarterly to reduce the number of checks they write each month. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our patients.

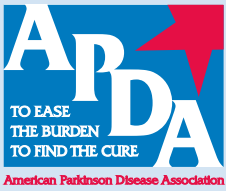
Our exercise classes meet once a week or otherwise as noted. Information that has changed since the last **LINK** appears in **bold**. Attend one class per week at no charge, or for \$20/month attend as many classes as you want. No RSVPs are required. Check our website, www.stlapda.org, or call to find out any changes since publication.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314.289.4202
Chesterfield	St. Louis	St. Luke's Deslodge Outpatient Center 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Sarah Farnell, OT	314.205.6934
Chesterfield	St. Louis	Friendship Village 15201 Olive Blvd. Friendship Hall-Door #5	Tuesday	1:30 PM	Jessica Andrews	636.733.0180 x7719
Chesterfield	St. Louis	Parkinson Resource Center 1415 Elbridge Payne, Ste. 150	Monday	1:30 PM	Tricia Creel, DPT	636.778.3377
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday or Friday	10:00 AM 11:30 AM	Craig Miller	636.778.3377
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday	10:00 AM	Bobby Lautenschleger, PTA	314.355.6100
Joplin	Jasper	United Methodist Church 1730 Byers Ave.	Monday	2:15 PM	Nancy Dunaway	417.623.5560
Kirkwood	St. Louis	RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear	Thursday	1:00 PM	Brandon Takacs	618.971.5477
Ladue	St. Louis	Tremble Clefs Singing Salem United Methodist 1200 S. Lindbergh Blvd. Lower Level Choir Room	Saturday	1:30 PM	Linda McNair, MT-BC	636.778.3377
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314.289.4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle	Tuesday	11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Winter Session Oct. 5-Dec. 11	1:45 PM Thursdays	Brenda Neumann	636.896.0999 x21
Greenville, IL	Bond	Bond County Sr. Center 1001 E. Harris Ave.	Wednesday	10:30 AM	Anna Oestreich	618.664.1465

**denotes non-affiliated APDA support group*

Do you have questions related to Parkinson disease and exercise? Please call the APDA National Rehabilitation Resource Center at Boston University - toll free helpline to speak with a licensed physical therapist who can answer your questions about exercise and identify exercise and therapy resources in your area.

TOLL FREE NUMBER: 888-606-1688 or Email at rehab@bu.edu



American Parkinson Disease Association
 1415 Elbridge Payne
 Suite 150
 Chesterfield, MO 63017
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Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list, or if you'd rather receive an electronic version. Just call **636.778.3377** or email **info@stlapda.org** to let us know! Thank you in advance for helping us spend our resources wisely!

Check out our Facebook page at www.facebook.com/APDAGreaterStLouisChapter



SAVE THESE 2016 DATES!

April 3:

Tools in Your Toolbox – A Panel Discussion

Who is a Candidate for Deep Brain Stimulation & Who is a Candidate for Duopa Gel?

What are the Pros and Cons of each procedure?

April 9-10

GO! St. Louis-Annual Walk/Run

Sewing THE Seeds OF Optimism



Steve Deines



Chris Kuesliauskas



Terri Brennan



Sandra Gaskill



Monica & Joel Perlmutter



Katie Byrum



Rebecca Bruchhauser



Jack Strosnider & Friends



Lauren, Emma & Kevin Fairlie



Debbie Guyer & Sherrie Rieves



2015 Fashion Show Highlights