

IN THIS ISSUE

Progress at the APDA Advanced Center for Parkinson Research	1-2
Blood Pressure and Parkinson's - What's the Connection?	3
Medications for Parkinson Disease	4-5
Snake Oil, the Cure for Parkinson's	6
Tremble Clefs Choir Partner in Research Study	7
A Reflection as We Approach a New Year	8
World Parkinson Congress News	8
Optimism Events	9
Going Digital	9
Tributes and Donations	10-11
Support Group Calendars	13-14
Exercise Class Calendar	15
Help Wanted	16



American Parkinson Disease Association

APDA Greater St. Louis Chapter

1415 Elbridge Payne Road, Suite 150
Chesterfield, Missouri 63017

636.778.3377 | www.stlapda.org



The printing and distribution of this newsletter was partially sponsored by a generous grant from Lundbeck.

Progress at the APDA Advanced Center for Parkinson Research

Joel S. Perlmutter, MD

This has been another exciting year for our APDA Advanced Center for Parkinson Research at Washington University. Our faculty has grown again with the addition of Dr. B. (Jay) Maiti starting as a faculty member this past July 1, 2016, after having completed his two-year fellowship with us. We were able to keep Dr. Maiti and support his training with a generous gift from donor, Mrs. Jo Oertli, which has now clearly reaped dividends with this development. Dr. Pietro Mazzoni also joined us from Columbia University in New York where he was a Movement Disorders expert for the last 15 years. Dr. Albert (Gus) Davis will be joining the faculty on January 1, 2017, after completing his fellowship, and Dr. Toni Pearson, a pediatric Movement Disorders specialist, also joined us on July 1, 2016. As you all know, we had an unexpected loss with the passing of Dr. Morvarid Karimi, who was the subject of the cover article in the last LINK newsletter.

A major area of research has focused on pathophysiology of cognitive impairment in people with PD. We published several papers describing findings of protein abnormalities in the spinal fluid from people with PD and how spinal fluid measures of alpha-synuclein (the protein that is abnormal in people with PD) correlate with CSF A-beta42 (an amyloid A-beta protein in the cerebrospinal fluid) and resting state network coherence in people with PD but not in people without PD. Ongoing work also suggests that changes in strength of a resting state network in the brain called the dorsal attention network may predict subsequent cognitive decline in people with PD and that at an early stage of PD this network may be abnormally strong (possibly in a compensatory role, but that is just speculation at this point). We are now in the process of revising this manuscript for publication.

We recently published a paper demonstrating that variants of the GBA, SNCA and MAPT genes influence PD risk, age at onset and progression (*Neurobiology Aging*). Much of this work demonstrates that people with PD also have abnormal brain deposition of

amyloid A-beta but that the distribution of this in most people with PD differs significantly from that in people with Alzheimer's disease. We also have found that marked deficits of non-dopaminergic neurotransmitters occur in people with PD and may play a role in non-motor manifestations. One of our past fellows, Dr. Jay Maiti, obtained a Parkinson Study Group Mentored Career Award, a one-



year grant to further explore the role of the cerebellum in the clinical manifestations of PD. Similarly, Dr. Kotzbauer was able to obtain a new five-year NIH RO1 grant to extend neurochemical measures from postmortem brains from participants in Perlmutter NIH RO1, and Dr. Kotzbauer's funding

will permit extending postmortem studies to an additional cohort of people with PD followed with careful motor and cognitive testing. So our studies in the area of cognitive impairments continue moving forward.

Investigation of deep brain stimulation (DBS) is still a major area of our research activities. We continue our studies to functionally map the region of the subthalamic nucleus (STN) using DBS in people with PD. We have focused this past year on developing and validating a more

continued on next page

APDA GREATER ST. LOUIS CHAPTER

Deborah Dalin Guyer, MA
Executive Director
dguyer@stlapda.org

Sarah Schmerber, OTD
Program Director
sschmerber@stlapda.org

Michelle Almengor, BA
Program Coordinator/Administration
malmengor@stlapda.org

APDA COMMUNITY RESOURCE CENTER

1415 Elbridge Payne ■ Suite 150
Chesterfield, MO 63017

Hours: 7:30 a.m.– 4:00 p.m. M–F
Phone: 636.778.3377

www.stlapda.org

BOARD OF DIRECTORS OFFICERS

Matt Schumacher ■ President
Rebecca Farris ■ Vice President
Ted Hume ■ Vice President
Kevin Fairlie ■ Vice President
Brian Hantsbarger ■ Treasurer
David Dankmyer ■ Past President

DIRECTORS

Dennis Barnes
Rob Goren
Joe Marchbein
Kathy Schroeder

DIRECTOR EMERITUS

Susan B. Levin

MEDICAL DIRECTOR

Joel S. Perlmutter, MD

NATIONAL AFFILIATION

APDA ■ 135 Parkinson Ave.
Staten Island, NY 10305
800.223.2732

EDITOR

Deborah D. Guyer

CONTRIBUTING EDITORS

Michelle Almengor
Ann Cook
Betty Hayward
Sarah Schmerber

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.

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.

Progress at the APDA Advanced Center for Parkinson Research. *continued from page 1*

precise method for identification of electrode contact locations in the brain. As part of this, we developed a new brain atlas for the subthalamic nucleus – a common target for electrode implantation in many people with PD. We are currently preparing manuscripts for publication on this work.

We have made major progress in development and validation of neuroimaging measures of PD severity. Of course, this is absolutely critical for us to determine whether any new treatment can slow disease progression. We have published several new papers describing and validating the use of new PET radiotracers to measure cholinergic neurons (a new vesicular cholinergic transporter marker) as well as a new PDE10A radioligand. PDE10A is important for signal transduction from dopaminergic neurons in the striatum. These radiotracers, along with the PDE10A radioligand, give us a clear picture on a PET scan of how dopamine and acetylcholine neurotransmitters are being utilized within the brain. Much of this work has been helped by seed funding through the APDA Center for Advanced Parkinson Research. A summary of the key findings from this work was published by Drs. Norris and Perlmutter in *Annals of Neurology*.

We also have made 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 published a 10-year-long study in *Annals of Neurology* demonstrating that carboxyfullerene given 10 days after a neurotoxin that selectively destroys dopamine neurons in the brain (those that are lost in people with PD) substantially reduces motor parkinsonism, increases PET measures of brain dopaminergic neurons, and increases the amount of dopamine in the striatum, the part of the brain that loses dopamine in PD. We have now begun studies to develop PET-based measures of target engagement for carboxyfullerene in preparation for human clinical trial. We are excited to move forward in this area as well. These preliminary studies have been supported in part by the Greater St. Louis Chapter of the American Parkinson Disease Association, and our hope is that donors will continue to contribute funds to the local APDA to support this exciting local research.

Dr. Racette and his team have continued to make progress in their studies of environmental risk factors for nigrostriatal injury, other epidemiologic work, and health-care delivery disparities in people with PD. In particular, they have published on nursing home and end-of-life care issues in people with PD, relationship of manganese exposure to development of parkinsonism and brain injury, and other relevant exposures and how they alter risk of developing PD. This work has included finding a genetic mutation that may make people more susceptible to manganese exposure which may contribute to injury in the brain that leads to parkinson-like features. Some of their preliminary data for their new grants was supported by the APDA including support to obtain large national databases for their epidemiologic work.

Dr. Earhart and her team continue to be highly productive with multiple studies published this past year on motor control of gait and balance in Parkinson disease and development of better tools to measure gait and balance. They also have been investigating the impact of different rehabilitation approaches on these problems. These studies have been highly influential on care of people with PD, and much of this work has been supported by the American Parkinson Disease Association and the participation of persons with Parkinson's in clinical trials.

These brief paragraphs highlight some of the PD research done by the APDA Advanced Center for Parkinson Research at Washington University, which the local Chapter funds at \$100,000 annually. This multidisciplinary team reaches across departments and programs to include a wide ranging group of faculty, staff, students, volunteers and supporters. These studies have been possible due to kind and generous efforts of our volunteers and their caregivers for their participations in many of these investigations. Of course, the Greater St. Louis Chapter of the APDA has supported many of the preliminary studies needed to start these studies that have subsequently been supported by the National Institutes of Health (NIH) and we hope will continue to do so. We have only been able to obtain these larger NIH studies with the preliminary data that we have been able to collect with Chapter support. We need to continue to work together as a team in our fight against Parkinson disease. ■

Blood Pressure and Parkinson's – What's the Connection?

Johanna Hartlein, RN, MSN, FNP, Nurse Practitioner, Department of Neurology, Washington University School of Medicine

Lee W. Tempel, MD, Movement Disorder Specialist in private practice in west St. Louis county.

Do you ever feel dizzy or lightheaded when you arise from chairs, the commode or your bed? Feeling lightheaded could be related to your parkinsonism. Parkinsonism causes motor symptoms like tremor, slowness, stiffness and trouble walking but also affects part of your nervous system called the Autonomic Nervous System (ANS). The ANS regulates your heart rate, blood pressure, bowels and bladder, and your ability to adjust body temperature and to swallow. Parkinson disease (PD) and ANS dysfunction can cause slow heart rate, constipation, different kinds of urinary issues, difficulty achieving or maintaining an erection in men, excessive sweating, and trouble swallowing foods or liquids. ANS dysfunction also causes what is known as orthostatic hypotension (OH) or drops in your blood pressure when you change position from lying down or sitting to a standing position. These drops in BP can cause symptoms of lightheadedness.

UNDERSTANDING BLOOD PRESSURE

Lee W. Tempel, MD

Blood Pressure (BP), while easy to measure, is the result of a very complex interaction between the forward pressure of blood, which is produced by the heart, and the resistance the blood meets as it travels through the blood vessels. The amount of resistance the blood encounters is dependent on many factors, such as how much blood is available, how thick it is, and the size and condition of the blood vessels. Throughout the day, your body maintains your BP- regardless of whether it is high, low or healthy- at a fairly constant pressure, which allows us to carry out our daily activities with minimal problems. If this BP maintenance did not exist, the simple act of standing up out of bed would cause everyone's BPs to drop and we would all faint immediately! Sometimes even healthy adults exceed the capacity of our bodies to automatically regulate our BP. For example, getting dehydrated, being out in severe heat or



standing too quickly are all stressors to the system that may result in fainting.

So how do we maintain a relatively constant BP as we go about our usual daily activities? That is taken care of largely by the Autonomic (automatic) Nervous System. In PD, as well as some other diseases (such as diabetes), patients can develop various degrees of ANS dysfunction, which results in the inability of the ANS to precisely regulate a constant BP. Because ANS dysfunction is more common in PD, these individuals are more at risk for low BP, which can cause symptoms ranging from very slight lightheadedness to fainting, in situations that wouldn't normally have dropped BP. This phenomenon of low BP as a result of change in body position is called orthostatic hypotension. There are occasional PD patients who have marked ANS dysfunction to the point that their BP drops drastically with standing, and this can contribute to gait instability, near-fainting, falls and even fainting. It is important to remember, however, that there are many other more common causes of gait instability in PD.

WHAT IS ORTHOSTATIC HYPOTENSION

Johanna Hartlein, RN, MSN, FNP

Not only does OH cause symptoms of lightheadedness, it can also cause other sensations like pain in the back of the head and neck (called coat hanger distribution), fatigue, mental fogginess, sleepiness, seeming zoned out, feelings like you will black out or even shortness of breath, chest pain, fainting or unconsciousness. "Lightheadedness" and "dizziness" are not the same thing. Being "dizzy" generally means a sense that you are spinning or that the room is spinning. Dizziness can usually happen in any position (sitting, lying or standing), and it is usually not associated with drops in your BP. Lightheadedness on the other hand usually happens when you have recently changed position (from sitting or lying to standing) and usually is relieved when you either sit or lie down from a standing position.

Medications used to treat PD also can drop blood pressures and cause lightheadedness. Although dopamine agonists (Pramipexole, Ropinirole, Neupro patch) and Amantadine can cause OH, so can Levodopa (Sinemet). This may cause a predicament for people with

continued on page 12

Medications for Parkinson Disease

Teresa Mangin, MD, Dean Clinic

Because medications play such an important role in living well with Parkinson disease (PD), it is important to have some working knowledge of why they are necessary and what symptoms they are intended to address. It can be equally important to understand what potential problems the medications can trigger in order to avoid living with a bothersome symptom that could be alleviated by a medication adjustment. Finding an effective PD medication regimen can be more of an art than a science, and it is definitely a collaborative effort between the patient and physician. What follows is a brief overview of the types of oral medications used to address the motor symptoms of PD, why they may be chosen at a certain point in time and what their potential disadvantages are.

Do I have to take medications for my Parkinson's?

With early or mild PD symptoms, you may not need medication. Many patients do well for quite some time with little or no medication after diagnosis. This obviously depends a great deal on what the presenting symptoms are and how much they are interfering with day-to-day tasks. Someone with a mild, intermittent rest tremor in their non-dominant hand may not be sufficiently bothered by it to justify potential side effects from a medication. On the other hand, someone with difficulty using their hand to write, cut their food, button their shirt, etc., would be encouraged to start medication to relieve the impairment and avoid the hand becoming weak from disuse. At this point in time, no medication has been proven to slow down or halt disease progression, and treatments are symptomatic only. That being said, patients whose symptoms are treated earlier and more aggressively tend to do better over the long run, probably by remaining as active and independent as possible.

How do PD meds work?

In general, medications for the motor symptoms of PD aim to restore balance of brain chemicals called neurotransmitters. Among these, dopamine is the most relevant in PD. Typically when PD is diagnosed, a significant amount of the brain's dopamine production has already been lost. The medications aim to boost dopamine pathways

in the brain so they may function at a more normal level. Many other neurotransmitters are impacted by PD and can be manipulated to treat certain symptoms. For example, acetylcholine is important for memory, but using drugs that block it can be helpful for tremor. Achieving the best balance for the individual patient can be a challenge and is often a moving

target.

Neurotransmitters allow communication between cells in the brain. One cell may make dopamine and release it; another cell has receptors that pick up the message, setting in motion a chain of events that allows for normal motor function. Receptors are a bit like locks that require a specific key. If insufficient dopamine is present, the lock remains locked and the message may not get through. (The brain may be trying to tell the foot to take a larger step, but the foot is not getting the right signals.) The receptors can be tricked with a skeleton key, or a dopamine agonist, that picks the lock and allows the message to get through, albeit not as precisely. The lock can also become jammed by dopamine antagonists, which block the signal from getting through even in the presence of a key. Understanding this basic relationship will provide a foundation for understanding how some of the medications work.

In addition to the components of dopamine and dopamine receptors, there are proteins between these communicating cells that clear away excess dopamine. These proteins can be blocked with the net effect of allowing more dopamine to remain in place, therefore having a better chance at binding the receptors. The examples of medications that work this way include COMT



Inhibitors and MAO-B Inhibitors.

Levodopa This is the oldest and best medication we have for treating the motor symptoms of PD. It is the most direct way of replacing dopamine. Levodopa is one step before dopamine in its production pathway, and it is changed to dopamine once it crosses into the brain. Straight dopamine cannot be given orally and get into the brain where it needs to work. Levodopa is always given with carbidopa, which blocks the metabolism or breakdown of levodopa in the bloodstream before it can make its way across the blood brain barrier. When you are given a prescription for carbidopa/levodopa, the second number always tells you how much levodopa is in the tablet. For instance, a Sinemet 25/100 pill contains 25 mg of carbidopa and 100 mg of levodopa. This medication has the advantage of being the cleanest and most potent way of addressing the brain's dopamine deficit in PD, but it has some disadvantages. It requires more frequent dosing than some of the other choices, typically given at least three times per day. Most patients do develop some motor complications after 3-5 years on levodopa therapy. These can take the form of dyskinesia and/or fluctuations between feeling "on" and feeling "off." Motor complications can be quite subtle for some people and very disabling for others, and there is not a great way to predict what will happen. Younger patients tend to be at higher risk for developing these complications, so often an alternate drug is chosen first in those cases. Contrary to popular misconception, levodopa does not stop working over time or lead to tolerance, nor is it toxic to the brain. Unfortunately, with disease progression in PD, higher doses can be required over time, but this reflects the decline in the brain's ability to make its own dopamine rather than diminishing effect of a given dose of levodopa.

Dopamine Agonists These drugs act on the dopamine receptors in the brain to trick the brain into thinking more dopamine is around than is actually there. They pick the locks of the receptors. Examples in this class are ropinirole, pramipexole and rotigotine. They have the advantage of less frequent dosing – all now have a

once-daily formulation – and lower risk of precipitating dyskinesia and motor fluctuations. However, they have a higher risk of cognitive side effects, sleepiness (even sleep attacks) and impulse control disorders (compulsive gambling or shopping, for instance). They are often used cautiously in young PD patients as a first-line treatment or as an adjunct to help smooth out the effects of levodopa later on. I use them with particular caution in elderly patients due to the risk of worsening memory, triggering hallucinations, and contributing to sleepiness during the day or difficulty sleeping at night. Some patients on these drugs also develop ankle swelling that should resolve when the drug is stopped.

MAO-B Inhibitors The options in this class are rasagiline and selegiline. They both block the protein that clears dopamine from the space between the sending and receiving cells in the brain. In doing so, they allow more dopamine to be present. Selegiline and rasagiline can be used for very mild PD symptoms on their own or as an adjunct to extend the duration of action of the other medications. For example, if someone is used to taking his levodopa every four hours and now it is starting to wear off at 3.5 hours, we might consider adding one of these with the goal of preserving a four-hour dosing interval. These drugs tend to be well tolerated, and are given once a day in the case of rasagiline and twice daily in the case of selegiline, but are not very potent when given alone.

COMT Inhibitors These work similarly to MAO-B inhibitors, blocking dopamine breakdown. Unlike MAO-B inhibitors, however, they are not prescribed as monotherapy. They are only given in conjunction with carbidopa/levodopa with the goal of making it last longer between doses. The COMT inhibitors are entacapone (Comtan or in a combo pill with carb/levo as Stalevo) and tolcapone (Tasmar). They can cause diarrhea in some patients and can darken the urine as well. They are typically given with each dose of carb/levo.

Anticholinergics These medications are sometimes used specifically to reduce tremor. Examples of anticholinergic med-

ications are trihexyphenidyl (Artane) and benztropine (Cogentin). They do not do much for rigidity or bradykinesia (slowness of movement) that PD patients may also have. They are difficult to tolerate, particularly in older patients. Common side effects include confusion/memory impairment, dry mouth, and constipation. I prescribe these medications infrequently due to their narrow role and risk of side effects, but they can be helpful in younger patients with difficult-to-control tremor.

Amantadine Amantadine is a unique drug in that its mechanism of action is not fully understood. It is thought to have some dopamine agonist and anticholinergic properties in addition to effects on the neurotransmitter glutamine. It is the only currently approved medication for treating dyskinesia, so it is often used in addition to other medications above if dyskinesia is becoming bothersome. It is also unique in that it is the only PD medication that does not cause sleepiness. In fact, sometimes we use it in an effort to keep people more awake during the day. It also can be helpful for tremor. Like the anticholinergics, it can cause cognitive side effects (confusion, hallucinations) and can sometimes cause a rash or ankle swelling.

Summary

Each patient requires an individualized treatment approach in PD. The medication regimen should take into account the patient's goals and his/her vulnerability to side effects. It is common to be on more than one type of medication to best control PD symptoms and minimize side effects. It is also very typical that the regimen will evolve over time with changing symptoms. Keeping a medication diary to note when medications are taken in relationship to timing of bothersome symptoms can be quite helpful. Don't hesitate to talk to your doctor or seek advice if you have questions! ■

This article is reprinted with permission from the APDA-Wisconsin Chapter. It first appeared in their newsletter, Parkinson's Perspectives, Winter 2014.

Snake Oil, the Cure for Parkinson's

Peter Dunlap-Shohl, NWPF Blogger

Did you know that Snake Oil will cure Parkinson Disease? It's absolutely guaranteed! I see some of you furrowing your brows and looking at me all squinty-like, as if you don't believe me. Oh ye of little faith! In spite of my hurt feelings, I will nevertheless be glad, eager even, to correct your sad paucity of vision, your cynical lack of faith.

Let's confront this head on. Have you ever seen a snake with Parkinsons? Of course not. These agile reptiles can move with great speed, and cover large distances, even without feet! No PD here, case closed.

But how can one spot genuine snake oil, and where does one get some? Have no fear, there are many people out there who will sell you snake oil for your PD. Step right up, friends, step right up! Here is how to find and obtain it.

First, there is no cure for Parkinson Disease. This is widely agreed by those who take the time and trouble to actually study this completed, difficult subject. The Michael J. Fox Foundation, the National Institute of Neurological Disorders and Stroke, and numerous universities and drug companies world-wide are working on this, but not one of these paragons of research has dared to claim to have found the cure. That there is no cure means the claim a product will cure Parkinson's is evidence it is snake oil. So look for those words "A Cure for Parkinson's Disease," before you buy. As of this writing, you can be confident the stuff advertised is real Snake Oil.

The Better Business Bureau has the following four tips on verifying if a claim for a cure is legitimate:

- Be suspicious of "miracle cure" claims. If a real cure for a serious disease were discovered, it would be widely reported through the news media and prescribed by health professionals - not buried in

emails, print ads, TV infomercials and websites.

- A red flag should go up if one product says it does it all. Be suspicious of products that claim to immediately cure a wide range of diseases. No one product could be effective against a long, varied list of conditions or diseases.
- Beware the line "It's all natural." Just because it's natural does not mean it's good for you. All natural does not mean the same thing as safe.
- Check with your doctor: If you're tempted to buy an unproven product or one with

questionable claims, check with your doctor or other health care professional first.

Not satisfied that the steps above establish that what you are being offered is genuine Snake Oil? Ask the person pushing the remedy how it works. They should have a plausible description of how the proposed treatment fits into the known pathways of how Parkinson's damages the body. If they cannot provide a credible explanation of why their wonder-cure works, Snake Oil, baby!

Also indicative of Snake Oil is a lack of a good-sized, randomized "double-blind" study, one in which neither those conducting the test nor those undergoing it know which subjects are getting the test substance or a placebo "sugar pill." This is the only way to sort out whether or not a substance truly has an effect on the disease. Anything else is likely, you guessed it, Snake Oil.

Where do you find Snake Oil in boundless, if not cheap quantities? The internet, of course. Web Sites, blogs and straight-ahead advertising all offer Snake Oil that you may shop for at home and have delivered to your door. As fast as a snake can carry it. ■

This article first appeared in the Northwest Parkinson's Foundation, September 12, 2016 edition and is reprinted with permission of the NWPF and blogger/author Peter Dunlap-Shohl.



Tremble Clefs Choir Partner in Research Study

Sarah Risso, Masters Student in the Program in Occupational Therapy at Washington University School of Medicine

Approximately 90% of people with Parkinson disease (PD) will develop speech and swallowing disorders throughout their disease progression. More specifically, those with PD experience reductions in the volume of their voice, poor voice quality, reduced pitch inflection, quickening of speech, dysfluent and/or hesitant speech and difficulty swallowing. Speech therapy, speech programs, music therapy and singing have all been used to address speech and swallowing difficulties associated with PD. Tremble Clefs, a nation-wide singing group for people with Parkinson's and their family members and care partners, aims to improve vocal quality and provide participants with social support. The St. Louis Tremble Clefs group, led by music therapist Linda McNair, M.A.Ed., MT-BC and accompanist Anna DiVesta, meets once a week and holds various performances throughout the year.

For the past two years, the St. Louis Tremble Clefs partnered with the Program in Occupational Therapy at Washington University School of Medicine in St. Louis to examine the effects of participating in Tremble Clefs. A total of 17 participants who regularly attended Tremble Clefs rehearsals were included in this research study. Data were collected every three months via questionnaires, in-person assessments during rehearsals and interviews with several group members. The physical effects of Tremble Clefs were examined using sustained phonation, which looks at how long a person can hold a note, and the Voice Handicap Index questionnaire, which measures the influence of voice problems on a person's quality of life. A satisfaction questionnaire and interviews were used to examine psychosocial effects such as social support, overall satisfaction and perceived benefits.

The sustained phonation and Voice Handicap Index questionnaire data showed mixed results: some participants improved in their voice and voice-related quality of life, some stayed the same and some declined. Although the group as a whole did not improve significantly on these measures, many individual



TREMBLE Clefs

participants improved considerably, and the interview results are consistent with this finding. Several participants perceived improvements in their voice from Tremble Clefs, others felt that Tremble Clefs was helping them retain their voice, and still others had not recognized any vocal deficits due to PD, yet thought that Tremble Clefs would help to prevent future vocal decline. For example, one member said, "The progress I have made didn't really just stop the decline of my problem but it has actually kind of reversed it so I speak in a much more normal tone. And

I have much greater ability with singing; I can sing much louder and my range is bigger. I can hold a note, sustained note, for much longer. So I have seen definite improvement in all of those things."

The satisfaction questionnaire and interview data indicated high satisfaction with, and some psychosocial benefits of, Tremble Clefs. In general, participants would recommend Tremble Clefs to a friend, were satisfied with the amount of help they received through Tremble Clefs, and were satisfied with program as a whole. Interviews with group members further supported the positive experiences that participants had with Tremble Clefs, including that it promoted a strong sense of community and social support and was enjoyable. One member said, "My experience with Tremble Clefs is strictly positive. Of the many classes I take, I look forward to it the most."

Our findings provide insight into the effect of Tremble Clefs and illustrate the benefits associated with the program. Although the group's sustained phonation and voice-related quality of life did not change significantly, some participants demonstrated and reported vocal improvements. Additionally, participants were highly satisfied with their Tremble Clefs experience and felt a strong sense of community and social support from it.

I would like to give a special thank you to Linda, Anna, and the wonderful Tremble Clefs members who allowed me to be a part of their group for the past two years. I learned so much from you all and am grateful for the time I spent singing and dancing with you. I wish you the best, and as always, keep singing. ■

A Reflection as We Approach a New Year

Debbie Guyer, Executive Director, Greater St. Louis American Parkinson Disease Association

I wanted to share a story that I recently had the pleasure of hearing, as I think you will find it to be quite meaningful as we approach the end of one year and beginning of a new year.

It was a story of a man who was having a lot of troubles so he went to a dear friend seeking his advice. His friend gave the man two boxes, one gold and one black, with these simple instructions. "Put all your sorrows in the black box, and all your joys in the gold box." The man followed the instructions depositing all his sorrows in the black box and all his joys in the gold box. And with each passing day the gold box became heavier and heavier, but the black box remained as light as the day before.

The man became very curious. "Why does the black box always seem to weigh

the same while the gold box keeps getting heavier and heavier?" So one day he decided to open the boxes. To his surprise he discovered a hole in the base of the black box where all his sorrows had fallen out.



He went back to his friend and had to ask, "Why did you give me a gold box with a solid bottom and a black box with a hole?" The answer was as simple as the directions

– "the gold box is for you to count your blessings and the black box is for you to let your troubles go."

It is easy to focus on the troubles and problems associated with having this dreadful disease—the things that have changed and those things which we must now make accommodations for.

As we make our resolutions and prepare for another new year, the story reminded me that we should count our blessings and the joys we continue to experience in life along with the hopes we have for an even brighter future. May it be one where Parkinson's is a thing of the past and where we exert control over living with our lives to the best of our abilities. May this be so! ■

World Parkinson Congress News

Sarah Schmerber, OTD, Program Director, Greater St. Louis APDA

Nearly 4,600 members of the global Parkinson community gathered in Portland, Oregon, from September 19 to 23 for a week of networking, inspiration, and groundbreaking science. APDA Greater St. Louis Executive Director Debbie Guyer, Program Director Sarah Schmerber, and chapter members Terri & Gerry Brennan, Mary & John Buck, board members Dave Butler and Kathy Schroeder, Support Group Facilitator and 2017 Walk Chair Doug Schroeder and Medical Director Dr. Joel Perlmutter attended the 4th World Parkinson Congress. The conference, which is held triennially, brings together anyone personally or professionally impacted by Parkinson's, including physicians, researchers, healthcare professionals, care partners, and individuals with Parkinson's.

It features a wide range of forums for attendees to learn more about Parkinson's, ranging from lectures to poster sessions to small groups and networking events. The World Parkinson Congress serves as a venue for sharing knowledge from across the world on the latest scientific discoveries, medical practices, caregiver initiatives and advocacy work. If you would like to hear about what we learned in Portland, please contact us and we would be happy to share! We also have a binder with slide sets from the majority of the presentations given, which you are welcome to review at our resource center in Chesterfield. If you are interested in attending the next World Parkinson Congress, it will be held in Kyoto, Japan, from June 2 to 7, 2019. ■





PAWS for PARKINSON'S

Rebecca Wells-Albers and her spouse, Nathaniel Albers, joined their friend Scott Newcomer in forming Paws for Parkinson's, a fundraiser to raise money and awareness for the American Parkinson Disease Association during this year's bicycle ride across Iowa (RAGBRAI- [Des Moines newspaper] Register Annual Great Bike Ride Across Iowa). The threesome pedaled 420 miles across southern (and hilly) Iowa and were encouraged by the many riders (over 20,000!) and the great food. All three considered riding RAGBRAI for years, but were inspired given the 2016 route, which passed through towns where Rebecca and Nathaniel have family connections. All three have a close connection with Parkinson's with Rebecca's and Scott's fathers both being diagnosed in the early 2000s. The Paws team have an affinity for cats - hence the Paws for Parkinson's theme and raised over \$1,500 for the APDA.



AARP 2016 ANDRUS AWARD

Goes to Greater St. Louis Advocacy Committee Member SHARON WELLS

AARP was founded in 1958 by Dr. Ethel Percy Andrus. Today, the AARP Andrus Award for Community Service established in her name recognizes outstanding AARP volunteers and members who are making a powerful difference in their communities in ways that support AARP's mission, vision and strategic direction and that inspire others to volunteer. The award was created in 2002 and each year honors one individual from each state. The Andrus Award is the organization's most prestigious and visible volunteer award and symbolizes that individuals have the power and ability to make a difference in the lives of others.



This year's Missouri recipient is APDA's own Sharon Wells. Sharon is an active volunteer on the APDA's Advocacy Committee. AARP contributed \$1,500 in honor of Sharon to our local chapter, and I want to express our congratulations and thanks to Sharon and her family. Sharon and her husband Russell celebrated their 50th wedding anniversary this year, and the Greater St. Louis APDA was the recipient of the many tributes (gifts) contributed in their honor. Paws for Parkinson's was an Optimism Event which the Wells children participated in this year raising over \$1,500 for the APDA.

CONGRATULATIONS to the Wells family for being such wonderful donors supporting APDA's mission, vision and strategic direction which will hopefully inspire others to volunteer and make a difference in the lives of others.

Hull of a Race

On August 20, 2016, the Mark Twain Area Support Group, hosted the 11th annual 5K/10K Race/Walk to raise money for research to find a cure for Parkinson disease. The group continues to strive to improve the event, providing an enjoyable but challenging certified course for the participants. We are proud to report that the Hull of a Race in Hull, Illinois has once again contributed \$10,000 toward the APDA mission (and we couldn't be more proud of their accomplishments and continuous support)!



Going Digital

Producing traditional printed flyers and mailings is pricey and not always the best use of donor funds. Regular communication with all of our readers and members throughout the United States is important but it can be difficult. Our intention is to continue to produce our printed quarterly newsletter. But, at times we need to communicate information about upcoming events and educational opportunities outside of the typical newsletter publication dates. For this reason, we have decided to expand the use of email when communicating with our member base, using Constant Contact. This expansion opens up a wide variety of opportunities for our members to further engage with the APDA and learn about the programs and services available to our community.

Stay connected to the Greater St. Louis APDA! It's easy to join our mailing list. Text APDASTL to 22828 to get started.

TRIBUTES & DONATIONS 07/01/2016-09/30/2016

Tributes are a thoughtful way of expressing sympathy, giving thanks, celebrating special occasions such as birthdays, anniversaries and 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.

IN CELEBRATION OF

B'nai Mitzvah of Max and Maya Bosse

Phillip & Sue Schreiber

Chris Edwards on his birthday

Paul & Carol Hatfield

Norma Koslow on her 85th birthday

Roselynn Gad
Gloria Ginsberg
Ellie Kassoff

George Meyer on his birthday

Fritz Mehner

Sara Myers on her special birthday

Pam & Jerry Brown

Ruth & Sylvan Sandler on their anniversary

Gertrude Hulbert

Elaine Varnadore on her birthday

Sharon Holt

Sharon & Russell Wells on their 50th anniversary

Bonnie Bolin
Ed & Shirley Hogan

IN HONOR OF

The APDA for their time and services in educating people about Parkinson's

Neil & Judy Weintraub

Mary Buck

Gayle Wheeler

Lois Decker for a speedy recovery

Jack Strosnider

Pat Denlow

Israel Denlow

Bill Gerth III

Erika & Bill Gerth, Jr.

Larry Glenn

Thank you for your years of dedication to the Camp Rainbow Foundation.

Debbi Braunstein
Barry Brimer
Mark Kronemer
Ken & Gina Rosenbaum
Lindsey Stokes

Sharon Hackman for a speedy recovery

Jack Strosnider

Paul Hatfield for a speedy recovery

Debbie Guyer

Bill Heidger

Nancy Bocklage

Norma Koslow

Eileen Mitchell

Charles Manley & Kimberly Perry

Dr. Donna L. Cartwright & Mr. Steven Smith

Joel Perlmutter for a speedy recovery

Debbie & Karl Guyer

Kathleen Sanders for a speedy recovery

Debbie & Karl Guyer

Sarah Schmerber, OTD

Janis Shannon

Jack Strosnider

Anonymous

Russ & Sharon Wells

Dale & Norma Plank

Sharon Wells on receiving the Andrus Award

AARP Missouri

Harry Weintrop for a speedy recovery

Beverly & Jerry Silverman

IN MEMORY OF

Joanne C. Abling

Christine Kempf

Vincent E. Beck

Vince & Rhonda Allaria
Cornejo & Sons
Brenda, Dan & Taylor Donohoo
Scott & Janna Evers
Charles & Maxine Foehrkalb
Jim & Sue Gallatin
Cletus & Betty Garde
Joe & Joyce Giardina
Wanda Graves & Robert Remmert
Genevieve Heepke
Ken & Jenna Highlander
Richard & June Iberg
Billy & Margaret Mainer
Jim & Sandy McCleish and Family
Barry & Carol Moore
Bob & Dolores Morrison
Claude & June Nealy
Don Noeth

Robert & Phyllis Reinneck
Arnold & Gerry Renken

Marian Reynolds & Family
Guy & Joyce Schmidt
Gary & Kathleen Schultz

Shirley Senn

LaVerna Shaffer

Al Slivka

Jean Stoff

Edward & Karen St. Peters

David & Christie Swanson

MiMi & Bob Townner

Rae Lee Trebing

Volleyball Girls

Marlin & Pat Wagner

Helen Wiemers

Walt Williams

Joan Bialczak

Elizabeth Berra

Glenn Bigham

Debra Bragg

Ed & Leasa Caperton

Lisa & Jacob Gamble

James & Rosalie Griffey

Darla & Chetley Herring

Bernard & Jane Martin

Ada Billings and in gratitude to Bill Billings

Kenneth & Jeri Wagner

Raymond "Jim" Boettcher

Kathy Disney

Roger W. Porter

Dennis & Andrea Westerfeld

Donald D. Bollman

Duck Club

Ralph Borgstede

Mary Lou Beare

Men of Beaumont

James & Bobbie Brock

Howard & Gerry Burmester

Rhea Cox

Friendship Force of Missouri-St.

Louis

Lois Hassinger

Ralph Katterhenry

Harry & Catherine Klein

Betty Urie

George Bossman

William Bernard Bahr

Barb, Doris, Brad, Jamie, Bruce,

Deb, Russ & Maria Decker

Marilyn & Bob Brangle

Patricia Degenhart

John & Deborah Einspanier

Lorene George

Ronald & Julie Gibbs

Wally & Beth Hayes

Helen Host

John & Clara Hudson

Sharon & Mel Ingram

Joseph & Lorraine Wrobel

Lorraine Bourner

Maury & Leah DeVos

Bonnie Reid

Al Brouk

Roland & Barb Lindhorst

James L. Buehne

Mary Buehne

Tom Buel

Leon & Carol Beck

Carolyn Buel

Frank & Karen Durham

Helen Eggen

Norma Jennings

Gary & Maxine Johnson

Jerry & Candy Robinett

Lois Silvey

Mary Steinmetz

Ruth Strobel

Mary Sundermeyer

Bob Winkler

William Cribbin

Jack & Peggy Cribbin

Kathleen D'Andrea

Debbie Shaner

Harvey Dobkin

Jerry & Pam Brown

Marvin & Sandy Muchnick

Connie Donius

Debbie Guyer

Jane Dothage

Donna Rehagen

Jeffrey Edelman

Pam & Jerry Brown

A. Glenn Edwards

Sandy Rider & Family

Shirley Eichler

Bernice & Mike Resnick

Roland Ernst Jr.

Bill & Mary Carol Fischer

Anita Fanning

John Fanning

Elaine Fox & Robert Ziervogel

Kevin N. Ziervogel

Gary Freund

Janet Freund

Harriet & Stanley Gellman

Terri & Billy Taylor

Georgia Lee "Sue" George

Barbara Fairfax

Tony Gerner

Patricia Anghilante

Abe Gersten

Bernice & Mike Resnick

Kathleen "Kate" Gibbs

Jeff & Linda Sandler

Margie Giraud

Allen & Sandy Holt

Robert & Sandra Kollar

Robert L. Goodson

Rosemary Albert

Jenny Baur

Barb Bingham & Sons and Duane

Helmkamp

Dorothy Braasch

Todd and Katherine Camerer

Curt, Mark & Carleen Carillon

Charles & Mary DeLong

John & Kristy Finney & Family

Mary Lou Finney

Rich & Donna Flagg

Jay & Alma Frohock

Glen Carbon, IL Support
Group

Roland Goodson

Wanda Graves & Bob Remment

Cliff & Judy Gruner

Lucy Hughes

Pat Imming

Kay James

Vivian Jordan

Paul & Ann Klemp

Evert & Joyce Lehman

Janet Little

Debbie Martin

Doris Meyer

Roger & Teresa Owens

Cheryl, Preetam & Rohan Pagar

Alice Potts

Robert & Paula Redman

Leona Rutz Family

The Scheib Family

Bob & Gloria Schwarz

Donald & Rae Simpson

Robert & Lynn Smith

Mr. & Mrs. Robert Stanley

Grace Sugg

Lindsey Toenyas

Lydia Tucker

Dennis & Lori Wernle

Joyce Zerban

Gary Zilles

Shirley Gordon

Barb Meyers & Family

Jack Louis Groszklos

Gail & Larry Glenn

Barbara Jean Grossman

Kathi & Stuart Rosenberg

Howard Grunewald

Tricia Thompson

Norman W. Hall

Rose Hall

Leo Hawkins

Pamela Hawkins

Mark H. Heeger

Jeffrey & Alvera Heeger

Don Hinze

Bob & Frances Dowdy

William & Bettie Dowdy and

Family

Mr. & Mrs. David Silverman

Larry F. Holder

Jackie Welsh-Holder

Dixie Holland

William Christie

Lois Horwitz

Rita Eiseman & Gary Zuckerman

Mary Goss Hughes

Crane Family

Debbie Guyer

TRIBUTES & DONATIONS 07/01/2016-09/30/2016

continued from previous page

Jim & Judy Hughes
Amanda Lucier
Walter Vandelicht

Rev. William Johnson
Phil & Jean Hampel

Dr. Morvarid Karimi
Daniel & Marva Lee Heumann
The Family of Glen Schaefer

Kenneth Paul Kastelic
Al & Carol Hofer

David Kelsay
Roy & Carol Hillmann
Mike & Bonnie Rich

Catherine Kruger
Bethesda Orchard Residents
Association
Richard & Barbara Buschart
Ruth Hohmeier

Toni Lynch
Cheryl Perl

Bess Maragos
Michael & Jo Ann Cornish
Gary Goldberg
Glenn & Nancy Leahy

Shirley M. McDaniels
Mary Lou Goedecker

Linda Meier
Jack Strosnider

Beloved Aunt of Anna Moore
Corey Rosenberg & Family

Arnold Mungle
Jim & Brenda Schlichter

Paul Myers
Phillip & Susan Schreiber

Mark O'Brien
Larry & Mary Ellen Adelsberger
Kay & Michael Bamvakias
Elizabeth Bode
Fred Brummel
Joe & Ginny Butkiewicz
Eileen Carlson
Judy Doerhoff
Mark & Diane Gorris
Dorothy Heckemeyer
John & Joan Hegedus
Carl & Sharon Kemna
Jean Kimpling
Jerry & Sue Knight
Robert & Geraldine Lanigan
Nita McAninch
Betty Miller
Kirsten Munck
Robert & Joan O'Brien
Tom & Kay Pile
Earl & Carole Stroud
Phil & Sallaine Upchurch

Mother of Jashana Perez
Cheryl Perl

Jim Peterson
Jean Peterson

John "Tom" Polansky
Jean Brown
Ronald & Charlotte Calhoun
Peggy Cline
William & Rosemary DeArmond
Wes & Millie DeProw
Mary Dolan
Carolyn Eaton
Amy & Jeff Edwards
Kyle & Jennifer Farrell and Sons
Dave & Peg Foshee
Dick & Martha Garner
Bryan & Judy Haynes and
Daughters

Alice Hopper
Kurt & Janet Koth
Jack & Priscilla Lunsford
Nancy Merz
Steve Morris
Bob & Lea Morrison
Lois Morrison
Bob & Gay Pape
Robert Pluenneke
Carol Rinehart
Jason & Paty Stine and
Daughters
Jeff & Kimberly Stine and
Daughters
Jerry & Carole Stine

Charles Przygoda
Consuelo Burkhardt
Claude & Kathleen Reis Cox
Friends & Neighbors
Harlan & Catherine Gast

Bob Reed
June Reed

Joseph P. Ritter, Sr.
Margaret Baumgartner
Craig & Judy Bryant
Mickey Chiecsek
Rachael Vogt Farrar
Interior Investments
Roland & Barb Lindhorst
Robert Pflieger
Harold & Mary Jo Rehg
Robert & Janice Ritter
Elizabeth Springfield
Jack Strosnider
Bill & Beverly Vogt
Jim & Chris Vogt

Mickey Roman
Cheryl Perl

Elfrieda Roth-Roffy
Paul Roth-Roffy
Bill & Beverly Vogt

Dr. Sudha Rani Saha
Charles Manley & Kimberly Perry

Patricia Schark
Michael & Joann Borglum

Dr. Maxine & Frank Gilner
Susan & Donald Meyer
Lee Dale & Norma Plank
John & Janet Strong

Don Schiffman
Mary Ann Baumann
James & Rita Blubaugh
Charles L. Nolan, Jr. & The
Duchesne High School
Community
Mae Robert

Elmer Schmuck
Gail & Larry Glenn

Marty Shrader
Steve & Judith Ellenburg
Judy Ugalde

Linda Sigman
Kathi, Stuart, Jamie, Laura &
Corey Rosenberg

David Sikes
Judy Betz
Richard & Norma Brune
Gary & Darlene Gansmann
Jana Thornton

Michael E. Small
Terry & Judy Esser Copeland
Deborah Knight
Cathleen & Kevin Marsch
Darrel & Mary Jo Newman
Connie & Rick Small
Gregory Wood

Aurelia "Skeeter" Speidel
Betty & Dale Kling
Thomas & Patricia Mathews
Nodiff & Billy-The Community
Association Lawyers
O'Connor Insurance
St. Louis Composting

Dearest Mother of Barbara Stein
Penny Kodner

Thomas Traber
Jim Carver
Rob & Nancy Fleer and Earl
Johnson
Michele Goodman
Terri Hosto
Jim, Kristine, Cole & Chase
Johnson
Steve, Tracey & Sarah Johnson
Patti Lodes
Angela Morenz
Thomas & Linda Muller
Richard & Carolyn Pakan
Shirley Parisi
Ken & Mary Perotta
Sandra Stocker
Jack Strosnider
Sharon Taylor
Jeff & Patty Waller

Jerry Vesper
Jerry & Pam Sherman Brown

Josephine Vietmeier
Pat & Jackie Wilson

Daniel Von Berg
Mary Burger
Gerald & Rosemary Carlson
Steven & Ellen Gall
Jane Kohl
Tom & Sharon McSwiggin
Dave & Pat Menzel
Tammy & Dann O'Connell
James & Peggy Raymond
DuWayne & Joan Renn
C.C. Richardson
Mark & Anne Rickmeyer
Robert Roads
Bob & Jeannie Schuller
Arthur & Jean Spiegel

Gordon E. Wall
Marilyn Wall

Ellen R. Wallch
Mark & Nancy Kodner

Wendy Whittington
Cheryl Perl

GENERAL GIFTS UP TO \$99

Lewis Billingsley
Gary & Nancy Boren
Linda Bouchard
Dick & Nancy Chin
Judy Cleveland
Terry Councilor
Lowell & Sondra Crow
Gerald & Cecile Davis
Rich Distler
Catherine Dunn
Ernestine Edelmann
Lila Eichelberger
Judith Fehrman
Richard & Patricia Gatz
Lucille Giffone
Robert Green
Ken Hammann
William Jamison
Edith Kapfensteiner
Bruce & Margo Kreycik
Elizabeth Lester
Christel Maassen
Peter MacNichols
Robert Mathieu
Linda McDonald
Les & Mary Muckerman
Vincent Mueller
Charles & Lynne O'Connell
Estella Pattin
Austin & Helen Peppin
Karen Pfitzinger & John Kehoe
Harvey Present
Joseph Price
Bob Sanderson

Judy Schuster
Patrick Scott
Myrna & Bradley Sexton
Irma Sissin
Beverly Spindler
Patricia Watson
David Wiese
Lois Carol & Dennis Wipke
Gene & Patricia Wittman

\$100-\$499

Robert Babione
Denise Brown
Margaret Bruno
Jean Cody
Don & Diane Donlon
Joann & Brian Elliott
Robert Guilander
Anne Herron
Steve & Linda Kilgore
Cheryl Kinert
A. Michael & Nancy Klein
Paul Krings
Kathy McVoy & Ken Dodds
Dick Meyerhardt
Darryl OBlack
Donald Pfarrer
Yolanda Prebianca
Janice & Patrick Scott
Ron & Rosemary Shadwick
Cynthia Smalley
Maudie Streetman
Arlie & Nancy Tempel
Jan Thomas

\$500-\$999

Bob & Linda Coulter

\$1,000 AND UP

Penny Kodner

THRIVENT CHOICE DOLLARS RECEIVED FROM

Donald Brohm
Lynn Smith
Robert Smith

PD who need their medication to be at their best functional level, but may then suffer from these unwanted side effects. In patients with PD, OH becomes more common as the disease progresses and becomes increasingly prevalent with older age, lower body weight and in people with thinking and memory problems.

OH is very common in PD with some studies reporting up to 56-78% of people with PD having this problem. In Multiple Systems Atrophy (MSA), the prevalence rises to 87% of patients. In MSA, there is a tendency toward more severe lightheadedness and even fainting, and it is generally seen earlier in the course of the disease. Since OH causes lightheadedness, it is also a big risk factor for falls. People with parkinsonism are already at risk for falls and with lightheadedness; this becomes a major issue for patient safety and quality of life. Aside from falls, OH also increases the risk of cognitive problems, the risk of overall mortality, and the risk of other cardiovascular or neurologic problems.

Symptoms of OH are commonly noted when a patient stands from a sitting or lying down position, but are also reported when the patient exercises, climbs stairs, bends over, bears down (when coughing or during a bowel movement) and when ill or dehydrated. For some people, it even occurs after eating a meal (postprandial hypotension). After we eat, our body's blood can divert to the stomach and intestines and pool there, causing BP drops and lightheadedness even in a sitting position. In people with postprandial hypotension, ingesting large meals can worsen this condition, and high carbohydrate meals may be more likely to cause drops in blood pressure after eating.

TREATMENT FOR ORTHOSTATIC HYPOTENSION

Lee W. Tempel, MD

There is no cure for orthostatic hypotension due to ANS dysfunction; what is done depends on how severe the dysfunction is. The goal is to enable the patient to remain able to stand and walk

without BP dropping too low to cause significant symptoms. Any or all of the following may be of help. To begin with, your doctor should review all of your medications, as he may choose to stop or reduce medications that excessively reduce BP. The second, and most critical, thing is to be sure to remain very well-hydrated by drinking LOTS of fluids (at least 1.5-2 quarts per day), starting sometimes even before getting out of bed in the morning and then drinking more earlier in the day and less later (so one isn't up all night going to the bathroom). Fluids with electrolytes, such as Gatorade, Powerade, etc., support BP better than water alone. Avoiding alcohol, prolonged exposure to heat and heavy exertion are important. Increasing salt intake also helps keep more of the fluid in the blood vessels rather than getting out into the tissues. Compression stockings (at least Grade 4) get more venous blood back up out of the legs to support central BP, but should be thigh high (rather than just knee high) and worn from the time one gets out of bed until going to bed at night. Raising the head of the bed at least 30 degrees is also helpful to avoid BP drop when first getting out of bed. While still sitting, pumping the feet and legs just before standing, especially if sitting for a longer time, can also help.

Despite all of these things, some patients will still need to consider talking to their doctor about taking medications that raise BP. There are several such medications available, but two are most commonly used: fludrocortisone (Florinef) which tells the kidneys to hold on to more fluids and midodrine (Proamatine) which puts more of a squeeze on the blood vessels. The physician adjusts these medications so that standing BP is acceptable, while realizing that this results in sitting and supine BPs that are somewhat high. These medications are used in such a way that their effect is mainly during the day when it is expected that the patient is sitting up and/or standing and, as such, may not be the best choice for patients who are going to be in bed all day. Consequently, they also have much less effect at night when patients are in bed. If the patient

is hospitalized and in bed all the time, the doses may need to be adjusted. In these patients, it is often important for aides, nurses and physicians to take BPs with the patient lying down, sitting and standing in order to judge the appropriate dosing. Healthcare providers often overlook taking BPs while the patient is in these different positions, so the patient and/or family members may need to advocate for themselves and alert care providers to this unusual situation requiring special attention.

Johanna Hartlein, RN, MSN, FNP

A third and newer medication is droxidopa (Northera) which has been used in Europe for many years and was approved by the FDA for use in the United States in February 2014. This drug is safe and generally effective with few contraindications. It must be ordered from a specialty pharmacy, but the manufacturer assists with the cost of the medication so it is as affordable as either midodrine or fludrocortisone. Many times patients will be prescribed two or three of these medications.

Whether you are taking one of the medications or not, the non-pharmacological measures to treat orthostatic hypotension are still important—especially increasing water and salt intake. If you do not have enough blood volume because of dehydration, the medications may not help!

Every person, with or without PD, may occasionally get up too quickly on a hot day or bounce out of bed too quickly in the morning and can feel lightheaded. If you are feeling lightheaded on a daily basis when you arise from a chair or bed, discuss this with your physician, as there are many ways to treat this common problem in parkinsonism. ■

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 at 636.778.3377 or the facilitator at the number listed below.

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	4th Monday	6:00 PM	Desma Reno, RN, MSN	573.651.2678
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	11:00 AM	Tricia Creel, DPT	678.951.3361
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 Region Medical Center Community Conference Room	3rd Friday	1:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Every Monday	3:00 PM	Nancy Dunaway	417.556.8760
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
South City St. Louis*	St. Louis	Cure PSP Group - St. Louis Altenheim 5408 South Broadway St. Louis, MO 63111	4th Friday	11:00 AM	Beth Evans	314.732.3433
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	2nd Thursday	2:00 PM	Valerie Givens, RN	417.820.3157
Springfield*	Greene	Parkinson's Caregivers Support Group Meyer Orthopedic and Rehabilitation Hospital 3535 S National Ave. Administrative Classroom	1st Wednesday	5:00 PM		417.269.3616
Springfield*	Greene	Parkinson's Young Onset Support Group Cox Medical Center 1423 N Jefferson Ave Meyer Center Conference Room C	4th Thursday	7:00 PM		417.269.3616



continued from previous page

Missouri Support Group Calendar

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Springfield*	Greene	Parkinson's Senior Support Group Cox Medical Center 1423 N Jefferson Ave Meyer Center Conference Room C	Last Wednesday	2:30 PM		417.269.3616
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Grooms, 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 Orchard - Parlor Room 21 North Old Orchard Ave.	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	Kellie Loughmiller	314.446.2589



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 at 636.778.3377 or the facilitator at the number listed below.

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	Britney Di Ulio	618.465.3298 x120
Belleville	St. Clair	Southwestern Illinois College Programs and Services for Older Persons 201 N. Church St.	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	Marion	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Betty Evans Helena Quaid	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	Mary DeLong Paula Beals	618.692.1346
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	Odd Fellow-Rebekah Home 201 Lafayette Ave.	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
Quincy	Adams	Quincy Public Library 526 Jersey St.	1st or 2nd Saturday- Please contact leader	10:30 AM	Terri and Dave May	217.224.7027



Exercise Classes

The APDA now offers 17 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 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 community.

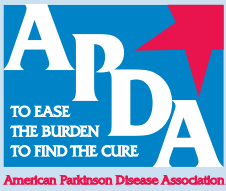
Our exercise classes meet once a week or otherwise as noted. Attend one class per week at no charge, or for \$20/month attend as many classes as you want. No RSVPs are required. Check our website, www.stlapda.org, or call 636.778.3377 to find out any changes since publication.

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	Travis Harper	314.223.9575
Chesterfield	St. Louis	Circuit/Interval Training 1415 Elbridge Payne, Ste 163	Monday Tuesday	2:30 PM 10:00 AM	Tricia Creel, DPT	636.778.3377
Chesterfield	St. Louis	General Chair Side Exercise 1415 Elbridge Payne, Ste. 163	Monday	1:30-2:15 PM	Tricia Creel, DPT	636.778.3377
Chesterfield	St. Louis	Tai Chi Parkinson Exercise Suite 1415 Elbridge Payne, Suite 163	Wednesday Thursday Friday	Intermediate- 10:00 AM Advanced- 12:00 PM Beginning- 11:30 AM	Craig Miller	636.778.3377
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Thursday	10:00 AM	Nancy Robb	314.869.5296
Joplin	Jasper	Mercy Hospital 100 Mercy Way Conference Room	Monday	2:15 PM	Nancy Dunaway	417.781.2727
Kirkwood	St. Louis	SSM Day Institute 1001 S Kirkwood Rd.	Thursday	1:00 PM		314.821.7554
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 (reservations)
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 Friday (New Participants)	11:00 AM	Holly Evans, COTA	636.916.9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Fall Session Oct. 3 - Dec. 9	2:00 PM Thursdays	Kathleen	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
Address Service Requested

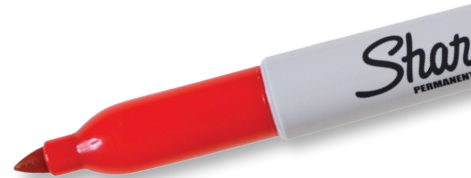
Non-Profit Org.
 U.S. Postage
PAID
 Permit #1032

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



Remember to use your eScrip card every time you check out at Schnucks grocery stores and earn dollars for APDA Greater St. Louis Chapter!



- HELP WANTED -

ARTIST LOOKING FOR COLLABORATORS

Clayton Petras, Master of Fine Arts candidate at Washington University in Saint Louis



I am looking to collaborate with individuals with Parkinson disease and its effects, specifically tremors, to create a body of work that delves into the narrative of mark making and personal portraiture. The handprint and footprint have always been an integral mark in the representation of one's personal history. They act as both a mark and a symbol. In contemporary art practice, we see the handprint emerge in works such as Jackson Pollock's 1A made in 1948 or in the many works of Jasper Johns. I look to continue this history with a new conceptual focus.

In this series of work, I wish to create with

you. I look to open up the possibility of an external agency of the body and to take the uncontrollable motion of something such as tremor and transform it into the sublime. This mark becomes an imprint, but also a passage of time, showing the shifting material moved due to the tremors.

This is a co-creative effort. The mark placed upon the paper is as much a part of you as it is my idea to do so. Therefore, in this project, I wish to be as personable and one on one with you OR as distanced personally as you wish, though I believe a personal relationship will yield a more effective work of art.

This is a very personal body of work to me. My mother was diagnosed with very early onset Parkinson's when I was young, and I therefore have a fairly deep and complex understanding of its early and transformative stages. Please contact me with further questions. I truly look forward to working with you, and am extremely excited about the possibilities in store.

Clayton can be reached at claytonpetras@gmail.com OR 509.570.3390. His website is www.claytonpetras.com

SEEKING YOUNG-ONSET FAMILIES!



Having a young family can be challenging in itself. Adding Parkinson's to the mix adds a whole new set of dimensions or complexities to the equation. If you are an individual with

Parkinson's or married to someone who has PD, and still have children living in your home, we would like to help arrange a get-together so that we can be responsive to your needs.

If you'd like to be a part of this group, please contact Debbie Guyer at 636.778.3377 or at DGuyer@stlapda.org so that we can get things started again in the area of Young-Onset PD which will help you share coping strategies and challenges that face those of you with young children and children living at home when a parent has Parkinson disease. We would love to have your interest and active participation in this new and exciting group.