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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 disease research.



The printing and distribution of this newsletter was partially supported by a grant from Medtronic.

I was fortunate to be able to attend the World Parkinson Congress 2013 held in Montreal, Canada, and was so inspired by Bob Kuhn, one of the Opening Ceremony speakers, that I requested permission to reprint portions of his welcoming speech to share with you. –Debbie Guyer

With Hope Unshaken

Bob Kuhn



Bob Kuhn

Although the world may see people with Parkinson’s shaking uncontrollably, struggling to move, weak and wobbly, let them also see our hope. A hope that knows the strength found in weakness, the fortitude in frailty, and the daring in disability. A hope that clings to the best of our dreams. A hope that presses on, not just for ourselves, the privileged few, but for a world that looks to us to lead the way. When all seems lost or far away, we must go on with hope unshaken.

We have come here to celebrate achievements made in our common quest for the cure. We are here to champion a better life. We are here to dispel the discouragement and despair that would dare to take away our *joie de vivre*, our love of life. We are here to share the warmth found in the confidence and courage of one another.

But more than that, we have come seeking something that will fight the fear of future days, the loneliness that creeps uninvited into our hearts. We have all come here to find hope, something to believe in. Hope that fuels our faith in the scientists and researchers who seek solutions. Hope in new medications that will provide relief, however brief, from the relentless advances of the disease. Hope in therapies and treatments that alleviate the pain. And hope that holds the hands of others half a world away. We come to fill our hearts with hope. With hope we are unshaken. Without it we are lost.

For me, it was January 19, 2006, a Thursday. I was not prepared for the words, “You have Parkinson disease.” I felt unready for the battle that lay ahead, afraid of the very foe that took my father’s life. It was the day I began to learn a secret.

As serious as many aspects of PD may be, I soon learned there is another more soul-crushing symptom. Parkinson’s is a self-isolating disease. For many people with the disease their world shrinks. As I began to notice my own propensity to withdraw, I also began to listen to the words that people with Parkinson’s were using. It was then that I realized the importance of pronouns.

In 2011, social psychologist and language expert, James Pennebaker, wrote The Secret Life of Pronouns in which he describes the power of personal pronouns. Consider the following facts: “I,” “my,” and “me” are three of the most commonly used words in the English language with the word “I” ahead of the pack. Studies show that “I” is spoken almost twice as much by people who are depressed. Conversely, the word “I” is spoken far less often by truly self-confident leaders. Further evidence suggests that consciously reducing your use of words like “I,” “my,” and “me” can improve the way you think and feel about yourself and the world around you.

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Changing one's personal pronoun usage is more difficult than you think. Most people have an overwhelming propensity to want to talk about themselves. Let me give you an example. At one point on my round-the-world trip, I was on the train from Cuzco, high up in the Peruvian Andes, to the extraordinary ruins of Machu Picchu. Seated nearby were some younger travelers from Australia.

I decided to try an experiment. The goal was to test how much I could get my fellow travelers to talk about themselves while disclosing as little as possible about myself. By the end of the two-hour train trip, I knew virtually the whole life story of a number of the travelers seated next to me. They knew virtually nothing about me. Not my name, my life story, or my special circumstances.

How have we become so self-absorbed? As with some of you, I was born into the post-war baby boomer “you-can-have-it-all” generation. Our generation stood up against authority and insisted upon our personal rights. It was the generation of “free love,” freedom to choose, live and let live, do your own thing; no wonder I grew up thinking that the world was all about me. And every subsequent generation seems to have built upon that self-oriented foundation.

One case in point: What is the current icon that defines our society? The... **iPhone!**

Whether our future is filled with success or struggle, dignity or disaster, remember the power of personal pronouns. We are not alone. We are linked, joined together as a “we.” Together, we can improve the quality of our lives. We can expand the scope of awareness and help people around the world. Together, we can, and will, find a cure for the plague of Parkinson disease. We are, together, people of hope who have the future in our hands, and we must reach out to the world around us. As we see our hope take root, grow and bear fruit, we must learn to share it with others!

In order to sustain hope, the global Parkinson community must be committed to coordinating its efforts. We must commit ourselves to collaborate, forgo petty self-interest, resolve turf wars and overcome our need to claim credit. If hope is to become more than hollow words, just another dream that disappoints, we must see our world differently. We must change the dominance of “I.”

How can we go on with hope unshaken?

What is that secret lesson I began learning on my diagnosis day more than seven years ago? It is committing ourselves to community. Perhaps you can remember it this way: What is the difference between illness and wellness? Illness begins with “I.” But wellness starts with “we.” ■

Tips & Tricks For My New Role

Are you a caregiver for your significant other or a close family member? Is it hard to manage your new role and chores around the house? APDA of Greater St. Louis, with the help of Washington University occupational therapy students, will be starting a special series of classes to help caregivers with role reversal in the spring. Classes may include money management, cooking, sewing, car maintenance, hair care, home repairs, etc. If you have any suggestions for our new role-reversal classes or are interested in more information on these sessions, please contact the APDA Center at 314-362-3299. Additional information about this special series, including start dates and times, will be in future newsletters and on our website, www.stlapda.org. ■

3rd World Parkinson Congress, A Patient's Perspective

Douglas Schroeder



I would like to share with you my experience in attending the 3rd World Parkinson Congress in Montreal, October 1-4, 2013. The Congress provided an excellent opportunity to further my understanding of Parkinson disease and its management. The registration booklet listed many sessions addressing my interests, including advocacy, genetics, and exercise.

There were over 3,150 attendees from 60 countries at this year's Congress. Parkinson stakeholders including scientists, doctors, patients, clinicians, and therapists were all represented. The purpose of the event was to provide global collaboration advancing science, inspiring hope, and community connection.

The event agenda was well structured, with sessions covering a variety of topics ranging from scientific research to patient advocacy. All sessions I attended allowed time for audience questions and answers.

Event Highlights

1. The full day Science and Advocacy course. It was a great start to the Congress, providing insight into research, treatment and management. Topics included levodopa delivery, DBS, neuroprotection, and ended with patient engagement and "What's taking so long?" Throughout the day, the knowledge and questions of patients in the audience impressed me.
2. An inspiring opening ceremony with a heartfelt caregiver speech and the award winning video "Smaller," an animation from New Zealand. It is posted on the St. Louis APDA website, www.stlapda.org.
3. Dr. Susan Bressman led a stimulating round table on genetic testing, discussing participant's family histories. Terry Ellis led an equally stimulating round table on exercise, hitting on the theme of keeping active.
4. First screening of the documentary, "The Astronaut's Secret," the story of astronaut Rich Clifford's experience with PD. Rich Clifford was there with the director answering questions after the showing.

Throughout the sessions there were many inspiring snippets. Some of my favorites were "Optimism is a choice," "Dopamine is not the whole story," and "FDA approval is not required for exercise."

From a patient's perspective, I found the event to be a valuable experience. I witnessed the passion of the community, heard firsthand the complexities in finding a cure, and noted the clear message on the importance of exercise. Attending was the right decision and I came away with a better appreciation of the Parkinson community. The next Congress will be held in Portland, Oregon, in late September, 2016. Join me in attending! ■

Letter From The President



Rebecca Daming

Rebecca Daming, President,
Greater St. Louis Chapter

Thank you for your contributions to the American Parkinson Disease Association (APDA), Greater St. Louis Chapter. Together, our work is changing the lives of a loved one or friend, and for patients like Christine, a young mother of two

who was diagnosed in her 30s. Some patients dream of walking again or returning to the dance floor. Christine dreams of attending her children's weddings. We are so grateful for your partnership which is making a difference in the dreams and lives of all of those patients and their families we serve.

Can you imagine life without Parkinson disease (PD)? Each year, for more than 132,000 individuals, the future of their lives, their independence, and health are drastically altered when they receive a new PD diagnosis. *Together, we are making a difference!* To meet the increasing demand of the PD community, last summer we significantly expanded our services and opened the Parkinson Community Resource Center. Through this center, we have experienced a dramatic increase in patient and family program participation. *By supporting these services, you are improving patient's mobility and quality of life.* As a very important partner, I am proud to share the return on your investment:

- Since 2010, *with your support, we raised more than \$1,000,000* to advance APDA's dual mission: to ease the burden and to find causes and a cure for Parkinson disease.
- Of that, *\$588,000 supported critical PD research*, with significant advancements reported weekly.
- Another *\$441,000 was dedicated to Parkinson patient services*, to assist patients, caregivers and family members. Our exercise classes, respite care, and support groups are provided at little to no cost.

Can you imagine investing in research that leads to a cure? We don't just hope—we believe there will be a cure. *Will you partner with us to find a cure by making a donation?*

As the holidays approach, our APDA family reflects on time spent with our own grandparents, parents, spouses, and friends who suffer from PD. We serve in their honor. We renew our deep commitment and investment in this mission. Join us by making a commitment of support today. The help we provide Christine and others depends on the generosity of partners like you. Thank you for your consideration and best wishes for a lovely Thanksgiving. ■

Questions for the Doctor



Dr. Pratap Chand

Pratap Chand, MD, FRCP, Professor of Neurology, Director of Movement Disorders, Department of Neurology & Psychiatry, Saint Louis University

Leah Cuff, APRN, ANP-BC, Nurse Practitioner, Department of Neurosurgery, Department of Neurology & Psychiatry, Saint Louis University (cuffle@slu.edu)

Q I noticed in Dr. Keith Roach's column that one of his readers, a Parkinson patient, found that Vitamin D greatly relieved his symptoms. Do you know anything about that?

A A study in Finland showed that patients with higher serum Vitamin D concentration had a reduced risk of PD. Another study in Japan showed that in patients with Parkinson's who took Vitamin D every day for a year, the disease did not progress as much as in those who took a placebo. But this effect was seen in only those who had certain types of a gene for the Vitamin D receptor.

Vitamin D can help with muscle strength and balance in the elderly population and thereby help the balance problems and muscle fatigue in patients with PD. There is ongoing research in studying the role of Vitamin D in PD. We recommend that patients with PD have their blood levels of Vitamin D levels checked and if it is low, to take Vitamin D supplements.

Q Our daughter has a child with egg allergy. She also knew that her dad had gotten flu shots in the past, but this year Jim had a bad reaction a few hours after the injection that lasted most of the night. We did learn that this year's injection was more potent, but we were not advised to forgo a flu shot.

A The flu can be serious for some individuals, especially the very young or elderly, people on immune suppressive medication, and people with chronic medical conditions. As with any illness, PD motor symptoms and cognitive problems can worsen while you are ill. With flu, you may have a fever and decreased fluid intake, and this can lead to dehydration and weight loss. An extended time in bed recovering from the flu can cause additional weakness leading to more difficulty with movement and increasing your risk of falls if you have balance problems. In general, it is recommended that patients with PD have the flu vaccination. However, if you have had a reaction to the flu vaccination in the past, there is a risk of reaction if you get vaccinated. Do discuss this with your primary physician.

Antiviral medicines can help reduce flu severity if started within two days of symptom onset but will not protect you from getting the flu. Oseltamivir and Zanamivir are examples of antiviral medications. If you do get the flu, you can discuss this treatment with your primary physician. ■

GETTING DRESSED

Elaine Benton



Elaine Benton

Struggles with zips and buttons,
are outweighed by far,

By the complexities, and
difficulties, of doing up my bra!

The clips are frustratingly small,
and usually at the back,

So no matter how I twist myself,
those clips I can't attack.

When finally my socks are on, and I'm near the
point of exhaustion,

I then tackle putting on my shoes, which takes
much contortion.

I'm horrified, after all that effort, to find that my
socks don't match,

But I'm far too tired, and it's now too late, for this
mistake to catch.

So often when I go out, not looking quite my best,

I may have non-matching socks, or forgot to button
my vest.

My makeup might well be smudged, with mascara
on my nose,

I'm a novel fashion disaster, from my head down to
my toes.

But I always wear a great big smile, and that's the
important part,

And forgiven any wardrobe error, as people see my
heart.

My eyes still twinkle as once they did, which should
give a clue,

That although today I look a mess, inside I'm just
like you.

So getting dressed can take some time, and best
done not alone,

Or I'd be ready to venture out, when you're on your
way home!

It's not a good feeling needing help, with such a
simple task,

But sometimes there's no alternative, and for help I
have to ask.

This poem can also be viewed on YouTube:
www.youtube.com/watch?v=2C6gDawqLjY or
on Elaine's website www.elainebenton.net. ■

Reproduced from Elaine Benton's book, Parkinson's, Shaken, Not Stirred, with author's permission.

Optimism Reigns!

Optimism Bowls

Richard Jacques hosted the second annual Bowl to Benefit APDA (Greater St. Louis Chapter) on July 13 and collected \$1,100 for research and patient services in the local St. Louis community. He honors the loving memory of his mother, Frances, who had PD.

Optimism Walks and Runs in Hull, Illinois

For the third year in a row, the Mark Twain Area Parkinson Support Group, under the leadership of Marilyn White, contributed \$10,000 in proceeds from the Hull of a Race 5K/10K Run/Walk event. This check was immediately forwarded to the National APDA to support research to find the cure. This year marked the eighth year for this event, held in the small town of Hull, IL, just outside Hannibal, MO. Each year this event has grown. This year there were 232 runners/walkers and 17 children who participated. Save the date of August 16, 2014, for next year's Hull of a Race.

Optimism Bakes

The Barnes-Jewish St. Peters Hospital and weekly Parkinson Exercise Group hosted their second annual bake sale on August 23 with proceeds restricted to support patient services. Together they raised \$670 which will be used to fund the many local patient services and programs, such as exercise classes, Tai Chi classes and aquatic exercise classes held weekly.

Optimism Creates Critters for a Cause

Sherry Wolz of Licking, MO, has created critters for a cause benefiting the Greater St. Louis APDA Chapter. Sherry attends craft fairs and has sold an array of cute critters resulting in \$82.06 donated in July and an additional \$197.66 this fall.

For more information about hosting your own Optimism event, contact the APDA office at 314-362-3299. ■



American Parkinson's
OPTIMISM

The Optimism Campaign recognizes individuals or businesses who contribute \$500 or more in donation and/or sponsorship of an event during each calendar year. These contributions were received between January 1 and October 25, 2013.

OPTIMISM 10,000 CLUB MEMBERS 2013

Community Partnership
at Benton Homebuilders
Wells Fargo Commercial Banking

OPTIMISM 5,000 CLUB MEMBERS 2013

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Truffles in Ladue

OPTIMISM 2,000 CLUB MEMBERS 2013

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KPMG
Dave & Christine Sadler
Matt & Annemarie Schumacher
Southern Illinois Parkinson Support Group
Jack Strosnider, Sr.

OPTIMISM 1,000 CLUB MEMBERS 2013

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Terry & Kathy Bader
Steven & Susan Barron
Kay Bruchhauser
Jean Byron

OPTIMISM 1,000 CLUB MEMBERS, CONT.

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Richard & Margaret Zimmerman

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

Joel S. Perlmutter, MD



Dr. Joel Perlmutter

I am delighted to provide this yearly update for the activities at the APDA Advanced Center for Parkinson Research at Washington University. We have had another excellent year of progress made possible by the support from the Greater St. Louis Chapter of APDA and all of our volunteers.

New Fellow—Dr. Tritia Yamasaki: Dr. Yamasaki began her post-doctoral fellowship in July 2013. She has been working in Dr. Marc Diamond's lab on a new project trying to identify new markers that may help in the diagnosis of PD. Her fellowship (like others in recent years including Drs. Norris and Ushe) is supported, in part, by the Chapter.

DBS: Investigation of deep brain stimulation (DBS) continues to be a major area of our research activities. We continue our studies on the effects of stimulation aimed at different parts of a part of the brain called the subthalamic nucleus (STN). The STN is the target for placement of the wires used in DBS for PD, but exactly which part of the STN should be stimulated remains a controversy. Drs. Eisenstein and Black's team has found a way to more precisely distinguish the effects of DBS at different parts of the STN. This is particularly important since different parts of the STN may have very different effects on movement, thinking, and mood. In a related study, Dr. Norris has determined how the location of the wire used in DBS may change after the initial surgery.

Thinking problems: In the last two years, we reported that thinking problems in PD are associated with widespread deposits in the brain of a protein called alpha-synuclein. In addition, almost 2/3 of people also have another abnormal protein called A-beta. Abnormal A-beta is well known to play a role in Alzheimer's disease, but we now believe that it plays a very different role in PD. We found that the distribution of A-beta in the brains of people with PD differs from that found in people with Alzheimer's disease, as demonstrated by PET scans that show where the A-beta is located in the brain. In addition, we have more evidence that these proteins in the brain are different in PD than in Alzheimer's disease by taking measurement of spinal fluid – the fluid that flows around the brain, which can provide clues about different chemical processes within the brain. These studies are important because they help us to identify targets for trying to treat thinking problems in PD, and that treatments for Alzheimer's disease may not necessarily work for PD. We are continuing our studies using PET, thinking tests, MR scans, genetic markers, and spinal fluid examination. These studies are led by Drs. Campbell, Foster, Cairns, and Kotzbauer, as well as Johanna Hartlein. This study was entirely funded by the Chapter. The study is now funded by a five-year grant from the NIH and a grant from the Michael J. Fox Foundation. We

still need more volunteers with PD with or without thinking problems and also need spouses or people without PD for comparison.

Brain networks: One of the hot new topics in brain research is to identify groups of different brain regions that work together for specific types of thinking processes. We call these groups of brain regions – networks. Much of this work is done with MRI scanning with a person lying quietly in a scanner. It turns out that while quietly lying like this, our brains seem to have a lot of background noise activity that can be measured with MRI. Careful analysis has found that seemingly random background brain activity (noise) measured by the MRI is actually different parts of the brain working together in synchronization. We call these synchronized networks “resting-state” networks since we can find them in people at rest. We published a paper about how these resting state networks are different in people with PD. Such changes may help explain problems with walking, balance and tremor. We also have found how some changes in thinking are associated with changes in other brain networks. These studies are led by Drs. Campbell, Snyder, and Susan Criswell. A key player has been Carl Hacker, an MD/PhD student at Washington University. Drs. Kristen Pickett and Gammon Earhart along with another recently graduated PhD student, David Peterson, have been using these methods to investigate the brain mechanisms underlying freezing of gait – the sudden cessation of movement that may occur when starting to walk, turning, walking through doorways or walking in crowds. They also are investigating different rehabilitation strategies to improve walking in PD.

Exercise: Dr. Earhart continues to be incredibly productive with her research team with multiple studies published this past year on various exercise and rehabilitation strategies to treat people with PD. Her studies range from ongoing dance therapy to using MRI scanning methods to investigate how various rehabilitation strategies affect the function of brain networks. This type of work may help to optimize treatment strategies and has already promoted dance therapy approaches for PD around the world.

Measuring Progression of PD: One key problem in testing new treatments to try to slow PD progression is to have a measurement of the severity of PD. Many different methods have been tried using brain imaging methods with PET or MRI scanners, but the methods may not have worked as well as hoped. We have made major progress in developing and validating brain imaging measures of PD severity. We just published findings that prove that most of the measures that have been used only work in the very early stages of PD, but after that, the measures in a part of the brain called the striatum (the part that has loss of the chemical messenger dopamine)

continued on next page

no longer reflect PD progression. However, we found that aiming the PET scanner at a different part of the brain called the midbrain, allows us to make good measurements of PD severity. The midbrain contains the brain nerve cells that make dopamine, and certain types of PET scans now permit us to measure the degree of loss of dopamine nerve cells. This work has been done by Drs. Morvarid Karimi, LinLin Tian, Steve Moerlein, and graduate student, Chris Brown.

Dopamine Receptors: Dopamine receptors are the key parts of nerve cells that permit the chemical messenger dopamine to communicate between nerve cells. Since PD causes reduction in brain dopamine, changes in dopamine receptors are important to help us design better drug treatments for PD. We recently published a paper that more clearly defines how the different types of dopamine receptors are distributed in the brains of people with and without PD. This study was led by Dr. Jinbin Xu. Other chemical messengers also are involved in PD, including one called acetylcholine. Dr. Xu has led development of a new PET tracer to permit us to measure nerve cells that use acetylcholine.

Treating PD: Finally, we have indeed made progress in the development of a medication that has potential to slow PD progression. This work has been done in collaboration with Dr. Laura Dugan at the University of CA in San Diego. She discovered a new drug called carboxyfullerene and we have completed a 10-year study that we have now submitted for publication. This study demonstrates that carboxyfullerene has potential to slow damage to dopamine producing nerve cells that degenerate in PD. Once this is published there are still many steps to

determine whether this will be an effective treatment for people with PD and will require several years of study. Of course, no studies can be done without FDA approval. Even if we obtain FDA approval for the study, it is possible that this drug may not work in PD. As I have said before, progress is made by hard, steady work. Quick short-cuts frequently lead us down the wrong paths, so please be patient with this line of research. Again, this work was initially supported by the Chapter and then by two separate NIH grants.

These are only highlights of the research currently going on at the Advanced Center. This research wouldn't be possible without the team of researchers consisting of faculty, staff, students, volunteers, and support received from the Greater St. Louis APDA Chapter. Drs. Racette, Willis and Criswell have also made some amazing progress and I only hinted at some of these studies. They continue to focus on environmental causes of PD and parkinsonism, the epidemiology of PD, and health care disparities. This work has potential impact on health care policy in this country and will be discussed in future newsletters.

Remember, volunteers and caregivers make this research possible. Chapter support has been and continues to be critical in obtaining preliminary data to allow us to receive NIH grant support. We make progress by working together. Of course, thanks must go to Debbie Guyer and all the efforts of the Chapter and the APDA Information and Referral Center, as well as to Susan Donovan who is the administrative assistant for our research center. We clearly depend heavily on these two incredibly effective people, and we appreciate all of their efforts. ■

Self-Management Workshop

Want to play more of a leading role in your disease management?

The Program in Occupational Therapy at Washington University School of Medicine is now offering self-management workshops to individuals with PD as a part of a new research study. Those enrolled will participate in the Chronic Disease Self-Management Program (CDSMP), a six-week class series that offers tools and information to help people manage their condition and participate fully in life. Interactive classes led by trained facilitators explore a variety of topics including:

- Managing symptoms such as pain, fatigue and difficult emotions
- Healthy eating and exercise choices
- Evaluating new treatment choices

- Appropriate use of medications
- Effective ways to talk with healthcare professionals and loved ones

Additionally, group discussion and collaboration help members develop appropriate goals and problem-solving strategies related to their disease. Study participation includes attendance at six, two-hour classes, once a week and agreement to other study requirements (questionnaires and a debriefing interview). There is no monetary compensation for participation but previous research on the CDSMP suggests a wide variety of benefits in adults with chronic diseases, including improved self-efficacy, decreased health-care costs, and prevention or delay of disability.

Who is Needed?

1. Volunteers must be diagnosed with PD.
2. Volunteers can be males or females over 30 years of age.
3. Volunteers must not be experiencing any problems with thinking and memory that interfere with their daily activities.
4. Volunteers must not have a history of brain surgery or other neurological problems besides PD.
5. People taking certain medications or with other serious systemic health problems (e.g., heart failure) will be excluded.

The principal investigator of this study is Dr. Erin Foster. For more information about the study and how to get involved, please contact Tasha Doty at 314-362-7160. ■

off the rack

Focus on Fashion & Philanthropy: 18th Annual Auction, Luncheon, & Fashion Show

Over 400 people joined us in the Versailles Ballroom at the Westport Sheraton Chalet Hotel on October 14, 2013, to support the APDA at the annual auction, luncheon, and fashion show. They happily took their seats after shopping for wonderful baskets and one-of-a-kind items during the silent auction. Courtney Landrum joined Victoria Babu as co-emcees, and they kept the commentary running and amusing. Dr. Mwiza Ushe spoke enthusiastically of the progress being made for people with Parkinson's and the promising research being conducted at Washington University School of Medicine. He also expressed his gratitude for APDA funding his fellowship and encouraged guests to continue their support



Dr. Mwiza Ushe

for patient services, programming, and research. Debbie Guyer shared her recent trip to the World Parkinson Congress and a video short entitled "Smaller – A Poem about Parkinson's." Honorary Chair, Jack Strosnider, spoke of his 25+ year connection to the APDA and his passion for helping those who are touched by Parkinson disease.

The event was a great success, raising over \$95,000 to support our mission, and we could not have done it without the help of our tireless volunteers. Lynda Wiens, Auction Chairperson, is the woman behind the creative and beautiful baskets. Our support groups, exercise classes, and fashion show committee brought wonderful items for the auction, and Lynda assembled them into enticing displays. Congratulations and our deep appreciation goes to our Fashion Show Committee members who went from shop to shop, restaurant to restaurant, collecting items and gift cards for the silent auction.



Debbie Guyer and Jack Strosnider



Katie Byrum & Rich Schindehette

Fashion Show Co-chairpersons Sherrie Rieves and Kathy Wunderlich gathered a lovely group of models and brought fresh ideas to the show. The guests were treated to fashions by new and returning boutiques as well as two local designers,



Peyton and Grant LaMartina

Luncheon favors were cookies in the shape of dress forms created by Candis Theodoro of CT Cookie Treats. And a special thank you to Aimee Bachman of Studio 9 Freelance Design who created the lovely dress form pin cushion centerpieces that were sold to benefit the APDA.

A heartfelt thanks to all the volunteers, bankers, and runners who made sure the event progressed smoothly. For many years now, volunteers from



Megan Yu, Karen Burkart, Amy Shands, Dee Dee Cortopassi

Elsevier have come to help with the auction as their day of giving back to the community. We also had many APDA volunteers who helped 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 photographs taken by and courtesy and video production by Larry Balsamo of Video Views, visit www.stlapda.org. ■

Photos courtesy of Cathy Hartman, Art & Soul Photography

including Details Women's Boutique, Distinctions, Lauren Bander, Panache Collection by Karen Burkart, PURE by Jen, and Savvi Formalwear. A round of applause goes to our 30 models and boutique owners and designers who selected fashions from their racks and fit our models for the show.

Wunderlich Fibre Box also sponsored the St. Louis Sirens to sing some familiar songs, with a humorous twist, to the delight of the audience.



Kozzy, Sherrie Rieves and Rich Schindehette



Julia Garlich and Sabrina Rallo

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listed on page 11



Dr. Anna Conti



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Tributes are a wonderful way to acknowledge the memory of a beloved person as well as honor those who mean so much to you. Tribute envelopes can be obtained from the Center at 314-362-3299. Contributions can be made directly on the APDA Greater St. Louis Chapter website, www.stlapda.org.

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continued on next page

continued from previous page

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Recognizing and Treating Non-Motor Symptoms in Parkinson Disease—Part 1

Okeanis E. Vaou, MD, Neurologist, Movement Disorder and Sleep Specialist, Noran Neurological Clinic PA, Minneapolis, MN



Dr. Okeanis Vaou

While motor symptoms are the most common in Parkinson disease and are used for diagnosis, the non-motor symptoms dominate the Parkinson's patient life and may also be missed in the doctor's visit. These include fatigue, depression, sleep disturbances, constipation, bladder and other autonomic disturbances (sexual, gastrointestinal, cardiovascular) and sensory complaints, such as pain. Other common complaints include bradyphrenia, confusion, dementia, lack of motivation, apathy, behavioral changes in mood and hallucinations. Based on the Braak theory, olfactory and autonomic disorders predate motor PD symptoms by 20 years.

A recent study of more than 1,072 PD patients revealed more than 98.6% had non-motor symptoms which were bothersome. In addition, medications used to treat the motor symptoms often-times worsen the non-motor symptoms, such as orthostatic hypotension.

PAIN

Many patients experience shoulder, leg or back pain prior to the onset of motor symptoms of PD. These patients are usually evaluated for pain by other specialists such as orthopedists, and diagnosed with arthritis or frozen shoulder. This pain is a constant dull pain, most of the time related to PD, and is usually relieved with PD medication. Another cause of pain in PD patients is leg cramps, which appear during off states or during walking, and improve with dopaminergic treatment.

HYPOSMIA

Hyposmia, the reduced ability to smell and detect odors, has been found to be a symptom preceding the onset of motor symptoms of PD by an average of four years. Decreased sensation of smell is not typically a common complaint of patients with PD, but in one study 45% of PD patients were anosmic, 57.1% were hyposmic and only 3.3% were normosmic. Hyposmia is now being studied to be used for early PD diagnosis.

AUTONOMIC NERVOUS SYSTEM

BLADDER

Urinary urgency is one of the most common symptoms in PD. Detrusor hyperreflexia and uninhibited bladder contractions cause urinary frequency and nocturia, which trouble patients with PD, waking them up at night and causing fragmented sleep. This usually adds to the preexisting bladder problems of BPH (Benign Prostatic Hypertrophy), which is prevalent in the elderly male group. Treatment of urinary urgency and

frequency with a peripheral antimuscarinic agent, such as oxybutinin, is helpful. A tricyclic antidepressant may also be used to improve sleep, as well as urinary urgency.

ORTHOSTATIC HYPOTENSION

Orthostatic hypotension may present itself as a feeling of lightheadedness, pre-syncope or syncope, may worsen cognitive state, and cause symptoms of fatigue, weakness or blurry vision. This happens because PD affects the autonomic nervous system and in particular, both the parasympathetic ganglion neurons and sympathetic cardiac plexi. This affects the vasoconstriction and blood pressure control. In addition, levodopa, dopamine agonists, and selegiline decrease blood pressure. Patients with PD rarely have orthostatic hypotension as severe as patients with MSA.

Increasing fluid and salt intake, compression stockings, and exercise to calf muscles are some of the conservative measures to increase blood pressure. However, if this is not enough to treat hypotension, Fludrocortisone, Midodrine or Pyridostigmine may be considered.

GASTROINTESTINAL

Due to parasympathetic dysfunction in PD patients, the gastrointestinal (GI) system is also affected. Gastric dysmotility with delayed gastric emptying affects digestion. Symptoms of bloating, reflux and indigestion are some of the resulting symptoms. Gastric emptying can also affect levodopa absorption, leading to medication failure or inadequate treatment.

One of the most common complaints among PD patients is constipation. This is due to many factors, such as parasympathetic dysfunction, decreased fluid intake and immobility. Usually increasing dietary fiber, vegetable, fruit and fluid intake, as well as exercise can be helpful. Medications commonly used, such as polyethylene glycol powder (Miralax) and other laxatives can adequately treat constipation. In severe cases, apomorphine can help with constipation. Studies have also shown that intrajejunal use of duodopa has helped with constipation and other bowel symptoms.

SIALORRHEA

Increased salivation and drooling are seen in 31% of PD patients. This occurs mostly because of decreased frequency of swallowing, rather than overproduction. Chewing on candy or gum is an easy way to overcome drooling and excessive salivations. If this is not effective, medications such as peripherally acting anticholinergics glycopyrrolate or propantheline can be helpful. In medically refractory cases, neurotoxin injections to the salivary glands can decrease production of saliva. ■

Article appeared in the Minnesota Messenger, Spring 2013 edition and is reprinted with permission from the Minnesota APDA Information & Referral Center. Part 2 continued in the next issue of LiNK.



Missouri Support Group Calendar

Sponsored by the American Parkinson Disease Association, Greater St. Louis Chapter

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

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 Nancy Rapp	636-532-6504 636-537-3761
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard	314-362-3299
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton Doris Heuer	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	Steve Balven Joe Vernon	314-249-8812 636-230-8279
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 Rich Hofmann	314-306-4516 314-369-2624
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Melissa McGuire Nancy Robb	314-355-6100 314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Mondays	2:00 PM	Nancy Dunaway	417-623-5560
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	314-286-2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy Dalton David Dalton	573-356-6036 573-434-4569
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	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	Last Thursday	11:00 AM	Kay Meyer	417-350-1665

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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, BSW	314-373-7036
Wentzville	St. Charles	Twin Oaks at Heritage Pointe 228 Savannah Terrace	1st Thursday	1:00 PM	Ann Ritter, RN Sherrie Rieves	636-336-3168 636-542-5400



Illinois Support Group Calendar

Sponsored by the Greater St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Jodi Gardner	618-234-4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, M.D.	618-549-7507
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	Kathy Broaddus	217-820-3096
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Marilynn Kozyak Jeanette Kowalski	618-288-3508 618-288-9843
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut—Meeting Room 2	1st Wednesday Apr.-June, Aug.-Sept.	6:00 PM	Karen Ladd	217-243-4904
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	Christ the King Parish Ctr. 930 Barberry Dr., SW Bldg. www.parkinsonssupportcentralill.org	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

Tremble Clefs

Tremble Clefs is a nation-wide program for people with Parkinson's, their family members, and care partners. The goal of this group is to be a participant-led, musical experience. Prior to the start of the group, the facilitator will gather input from interested participants on the structure and expectations for the group. Through vocal exercises, singing as a group, and playing instruments, members will come together and bond over a shared joy of making music. This experience will take advantage of the many physical and emotional benefits of singing. The Tremble Clefs singing program can help address voice and communication problems through breathing, stretching, posture activities, vocal exercise, rhythm and movement, and a strong social support system. Additionally, by engaging members of the Parkinson community in this meaningful, social activity we hope to promote increased confidence and well-being.

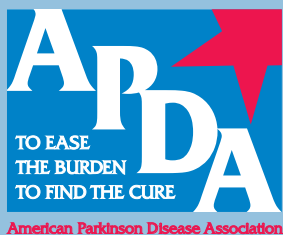
If you are interested, please contact the Center at 314-362-3299. We anticipate this program will start in the spring, and have already begun to accept names of people interested in group singing and this musical experience. ■



Exercise Classes

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.

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 Hospital 232 S. Woods Mill Rd.	Tuesday	11:00 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	Gardenview Chesterfield 1025 Chesterfield Pointe Parkway	Thursday	1:00 PM	Brandon Sunderlik Faye Bienstock	618-971-5477 314-917-9983
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	314-362-3299
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Monday	1:00 PM	Susan Mayer, MHSPT	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Fall Session Oct. 7-Dec. 10 Winter Session Jan. 6-Mar. 14	1:00 PM Tuesdays	Brenda Neumann	636-896-0999 x21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Monday	2:00 PM	Nancy Dunaway	417-623-5560
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314-289-4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Healthwise Center 6 Jungermann Circle	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, COTA	636-916-9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Fall Session Oct. 7-Dec. 10 Winter Session Jan. 6-Mar. 14	2:00 PM Thursdays	Brenda Neumann	636-896-0999 x21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534



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 American Parkinson Disease Association
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Check out our new Facebook page, at www.facebook.com/APDAGreaterStLouisChapter

Keep up with the latest news, program information, and share articles and photos with Facebook friends.

LIKE US and spread the word!

2014—Save the Date!

Join the APDA Team of Runners and Walkers at the 2014 GO! St. Louis Marathon & Family Fitness Weekend



We are honored and excited that our chapter has been chosen as an official charity of the 2014 GO! St. Louis Marathon & Family Fitness Weekend to be held April 5 and 6. When you walk or run for Team APDA, you will be playing a key role in helping to raise awareness of Parkinson disease. Each participant is asked to raise a minimum of \$250 which will be used to fund Parkinson research. Our

goal is to raise at least \$10,000 this first year as part of GO! St. Louis. The four main events a participant can choose from are Marathon, Marathon Relay, Half Marathon, and 5K Run or Walk. The 5K will be held on Saturday, April 5, in Forest Park, and the rest of the events will be on Sunday, April 6, in Downtown St. Louis. There is also a kids fun run and Mature Mile for adults 60+ on Saturday.

In order to join Team APDA or to volunteer on Sunday, April 6, please contact Michelle Brooks at 314-362-3299 or brooksmi@neuro.wustl.edu. After completing a commitment agreement, participants will be given a discount code to use when registering online. We encourage you or your friends and family to sign up early as some events do sell out. The walk/run committee is also looking for corporate and individual sponsors to help defray the cost of Team APDA shirts. ■

February 2

Parkinson Education Program (PEP) on Deep Brain Stimulation (DBS)

Program will consist of a panel of experts on DBS (Drs. Pratap Chand (SLU), Terry Rolan (MU), Mwiza Ushe (WUSM)). Discussion will include who is a candidate for this surgical treatment, what is involved in the surgery, and what can I expect after the stimulators are turned on. SPECIAL GUEST APPEARANCE by Brent Peterson, former professional NHL ice hockey player, and coach and director of operations for the Nashville Predators, who will share his personal story of his toughest faceoff and DBS experience. Brent will be joined by other Blues hockey greats – so don't miss this special opportunity to learn about DBS and be inspired.

April 5-6

2014 Go! St. Louis Marathon & Family Fitness Weekend; Downtown St. Louis.

Visit www.stlapda.org to register for this event.

May 19

APDA Annual Golf Tournament honoring the memory of Jack Buck. Tournament will be held at Algonquin Golf Club.