LINK

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Greater St. Louis Chapter

Serving Missouri and Southern Illinois

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APDA
TO EASE THE BURDEN
TO FIND THE CURE
American Parkinson Disease Association

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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.

We Have a Choice - The Impact of Attitude

Peter Gall described Parkinson disease as "a collection of symptoms, not all of which are exhibited in every case. Most of them have to do with our inability to control our personal locomotion system. We command our brain to take a step, and the brain responds, 'Good luck!'" You can't change that you have Parkinson disease, but you can change how you live with it.

Charles R. Swindoll's thoughts on the impact of attitude reinforce this idea. He writes, "The longer I live, the more I realize the impact of attitude on life. Attitude, to me, is more important than facts. It is more important than the past, than education, than money, than circumstances, than failure, than successes, than what other people think or say or do. It is more important than appearance, giftedness, or skill. It will make or break a company…a church…a home. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change our past…we cannot change the fact that people will act in a certain way. We cannot change the inevitable. The only thing we can do is play on the string we have, and that is our attitude. I am convinced that life is 10% what happens to me and 90% how I react to it." And so it is with you – we are all in charge of our attitudes.

John O'Leary, a motivational speaker, touched on this same theme in his Rising Above journal entry on November 25, 2013. "Over the last six years I've had the honor of sharing my message with hundreds of thousands of people around the world. During this time I've met unforgettable individuals with unforgettable stories, remarkable courage and unbreakable spirit. Meeting these people has been amazing, but the most remarkable person I've found was not on the road, but at home." He continues, "For more than two decades one of my heroes, my dad, has battled Parkinson disease. It is a degenerative disorder that gradually impacts everything physically. In time, Parkinson disease rips away one's ability to work, type, write, drive, walk and speak. As a result, it becomes increasingly difficult to socialize with others or participate in personal hobbies. As obviously difficult as this disease is for my dad, it amazes me that I've never heard him complain.


John and his dad, Dennis O'Leary

"I asked Dad how he remains so positive when dealing with such difficulty. He responded that he couldn't possibly be negative when he's got so much to be grateful for. I then asked him to share with me three things he's grateful for as a result of Parkinson disease. Dad responded immediately:

- I am grateful it wasn't a more serious disease.
- I am grateful for the time to reflect on who I am and who God is.
- I am grateful for my relationship with your mom; we've grown even closer.

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"Here is a disease that rips everything from the sufferers (and he is grateful it wasn't worse), forces them into isolation (and he is grateful for time to reflect), and causes them to be dependent on others (and he is grateful for that relationship). I stood to give my dad a big hug. He quietly but firmly said to me, 'Sit down, John. I'm not finished.' He continued:

- I am grateful for medical technology – and those who provide it.
- I am grateful for the empathy I've gained for others with challenges.
- When I can't walk or speak, I am grateful for the days I could.
- When we drive, I am grateful for the handicap spot.
- I am grateful to still see, hear, learn, laugh and love.
- I am grateful for being healed, even if not cured.

"This terrible disease, his intense physical pain, the stress on my mom (another one of my heroes), his inability to earn a living, the resulting financial struggle and his immobility have led to some of the greatest gifts in my dad's life, because he chooses to look for them.

"We all know people who have everything and are grateful for nothing. We also know others who have nothing and are grateful for everything." John concludes that "choosing to seek good each day in their challenges, their opportunities, their relationships and their world will result in the reward of unlocking even greater gifts tomorrow." ■

That's A(nother) Winner!

The annual APDA Golf Classic in memory of Jack Buck will take place May 19, 2014, at Algonquin Golf Club in Glendale, MO. Mark your calendars! Invitations will be mailed out soon, so don't delay in returning your registration as this event sold out early last year.

St. Louis Cardinals GM, John "Mo" Mozeliak, will serve as Honorary Chairperson for the fifth consecutive year. Mo's Parkinson connection is twofold as both his grandmother and father-in-law were diagnosed with Parkinson disease. One of the highlights of the evening is the Q&A session with John Mozeliak and broadcaster Dan McLaughlin. Last year, over $110,000 was raised to support local patient services and programs and to fund Parkinson research. Participants commented that they enjoyed the sit-down dinner and feasting on Chef Brian Bernstein's delicious creations. If you don't golf, there is a dinner-only option, but tickets are limited, so sign up early.

If you or someone you know would like to receive an invitation to play in this wonderful tournament, become a corporate or individual sponsor, and/or donate a gift for the auction or raffle, we welcome your involvement. Please contact the Greater St. Louis APDA Chapter at 314-362-3299 or send an email to brooksmi@neuro.wustl.edu.

Help us honor Jack's memory with another winner! The funds generated will assist those living with Parkinson disease in our local communities as well as the researchers hard at work discovering causes and ultimately a cure for Parkinson disease. ■

I Live in Hope

Elaine Benton, www.elainebenton.net, reprinted with permission from *The Huffington Post*, April 2013 edition

Have you ever looked in the mirror and wondered who on earth is staring back at you? Parkinson disease is slowly stealing away my smile and expression. If I were a poker player, this would give me a distinct advantage, but other than that, it's very difficult for others to know what I am thinking. I barely recognize myself anymore; the reflection staring back at me has no expression, just a blank empty look.

An experienced doctor, despite spending years specializing in a particular field, can he really visualize and understand what it's like to live with a degenerative disease? Unless standing in a patient's shoes, it's impossible to grasp completely the daily complexities encountered with chronic disease. Parkinson disease, like many neurological diseases, continually persists and never gives up. I've long forgotten what it feels like to feel no pain, to move my body freely, walk briskly or dare to run. How I miss those simple pleasures I once took for granted. I mourn the parts of me I've lost, my abilities and activities I can no longer do, and things I will never see. Left with no choice, I embrace the "new me" as this is all I can do. I'm someone slightly different, a re-vamped Elaine, still fundamentally "me," yet changed in many ways.

With Parkinson disease I never know whether I'm going to have a good or bad day, and making arrangements in advance can sometimes be risky, uncertain what state I will be in on that particular day. When having a good day, it's great, and although my walking is still poor, and I have terrible dexterity in my fingers, I put up with the many symptoms, taking advantage of a good day, and achieve as much as I can. To have a productive day, go out somewhere or have visitors over, is great when I'm feeling good.

On a bad day, it's an entirely different story and you probably wouldn't want to be around me; I don't think I would want to be around me! A bad day is when my voice can hardly be heard and it's an effort to even talk on the phone, shaking and tremors are exacerbated, walking from one room to another becomes a challenge, and I'm barely able to think or make decisions - it's all just too much, an overwhelming feeling that I simply can't take any more. No matter how cheerful and positive I remain, and I'm fairly upbeat most of the time, on occasion, my spirits sink, and Parkinson disease unfortunately gets the upper-hand. At these times, only a fellow sufferer can fully understand. I just want to curl up in bed, pull the covers over my head, and hope to be granted grace and magically disappear from this world. A more honest description of a bad day, I cannot manage.

As strange as it may sound, some things have changed for the good. I no longer worry what people think of me, or need to put on the graces. I have been given the opportunity of being "free" to speak out, to connect with others I may have never had the pleasure to meet, to be part of something so much bigger than myself, a sort of global Parkinson disease family, all fighting for the same cause. Each of us can make a difference; together in numbers we have strength and the power to bring about change. April is Parkinson Awareness Month, which hopefully brings greater public understanding to a disease that millions suffer from around the world.

Parkinson disease affects every aspect of one's life including that of family and friends who are brave enough to stick by through thick and thin. With heightened awareness, the vast amount of research and development going on around the world, and new procedures producing positive results, doctors and scientists are tirelessly working to come up with a cure, as if in some sort of race. It is indeed a race, for many of us are running out of time.

I daydream, wondering what it would feel like to be cured. No more nasty symptoms and side effects from the many medications patients depend on to make it through each day. I close my eyes to imagine what it would be like to live a normal life again, to stroll hand in hand with my husband along the sea front, to walk briskly with my dog through the forest, or even something as simple as getting out of bed unassisted. Some dream of fame or fortune, others of winning the lottery, but I dream of the day a cure is discovered and made available to all those in need. I live in hope. ■

Recognizing and Treating Non-Motor Symptoms in Parkinson disease—Part 2

Okeanis Vaou, MD

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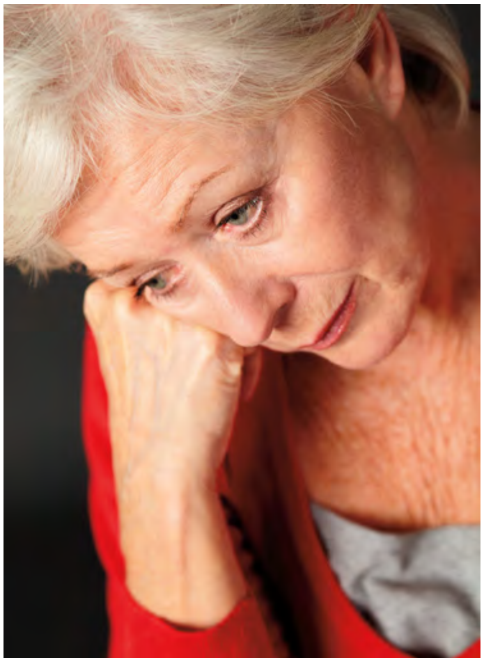
Part 1 appeared in LiNK Novemer 2013.

While motor symptoms are most common in Parkinson disease (PD) and are used for diagnosis, the non-motor symptoms dominate the Parkinson disease patient's 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 and apathy, behavioral changes in mood and hallucinations. Based on the Braak theory, olfactory and autonomic disorders predate motor PD symptoms by 20 years.

DISORDERS OF BEHAVIOR

Depression

One of the most common concerns in PD patients is depression, which may precede motor symptoms of PD, or occur as PD progresses. One study showed a 28% prevalence of depression in PD patients. In a different study, depression affected 45% of PD patients. Depression in patients with PD is a factor of impairment of activities of daily living.



There have been several suggestions for the reasons for depression experienced by patients with PD. A patient with PD faces many challenges due to his or her motor disabilities, and may have to give up a fraction of his or her independence. This, along with the diagnosis of an incurable, chronic and debilitating disease, increases the risk for depression. On the other hand, the pathology of PD itself may be the cause, affecting the serotonergic and noradrenergic neurons in the limbic system, typically involved in primary depression.

The recognition of depression in PD patients is very important, and treatment can improve activities of daily living. Most commonly, SSRIs are effective in treating depression. Of the dopamine agonists, pramipexole, used to treat motor symptoms of PD, has shown antidepressant activity similar to fluoxetine, and was better than a placebo in 174 patients with PD and depression.

Anxiety

Anxiety frequently coexists with depression in patients with PD. Patients feel anxious in social or professional settings, and fear that they will not perform adequately, or that their friends and relatives will notice their motor or verbal disabilities. Anxiety also tends to worsen during "off" states. Treatment with dopaminergic therapy is usually effective in treating anxiety.

Depression and anxiety can also occur as the sensory or behavioral "off." Similar to the motor "off," this occurs when there is insufficient dopaminergic activity, mostly to the limbic system and therefore responds to dopaminergic therapy aimed at preventing wearing off.

Lack of Motivation

Personality disorders may manifest as a lack of motivation and restriction of activities. The patient may find it difficult to multitask or make important decisions at work, and may not be able to continue working. The patients become more passive and dependent on their caregivers. They tend to become less interested in social activities and prefer to stay home. In severe cases, the patient develops apathy and abulia with complete lack of motivation and initiative. Such changes may be related to depression, but most times there is no mood change. Although dopaminergic therapy can be effective, a small study has suggested that stimulants such as mehtylphenidate have proven to be effective.

COGNITIVE PROBLEMS

Dementia

Unfortunately, in the late stages of PD, a large portion of patients develop dementia. PD dementia is characterized by impairment in attention, memory, executive and visuospatial functions. In addition, behavioral symptoms such as changes in affect, hallucinations and apathy are frequent. Dementia can affect up to 80% of late stage PD patients. According to one study, patients with akinetic-dominant or mixed tremor/akinetic PD have a higher risk of developing dementia. In a different study, it was found that patients with end stage PD who had dementia had worse "on" and "off" motor periods and a smaller response to levodopa. Treating dementia in PD patients can be challenging at times. Before treating dementia in patients with PD, secondary and potentially reversible causes need to be ruled out. Such causes include infection, metabolic abnormalities, subdural hematoma, hypothyroidism and seizures. Medications which are frequently used in PD and can worsen dementia should be decreased or discontinued. These include selegiline, anticholinergic medication, amantadine and dopamine agonists such as pramipexole and ropinirole. Donepezil and Rivastigmine have been shown to provide moderate benefit in dementia. Hallucinations, which frequently coexist with dementia in PD

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patients, can be treated with quetiapine without exacerbating Parkinsonian symptoms. Clozapine is also effective in treating hallucinations; however, weekly checking for neutropenia makes this a less favorable choice.

Hallucinations

Visual hallucinations are reported in 16-37% of drug-treated Parkinson disease patients, and are the most common hallucinations in PD. Auditory hallucinations are relatively uncommon. Hallucinations are perceptions that are not based on any relevant stimulus. Delusions are false, irrational beliefs that are not based on data. In general, these are distinct phenomena, although both may occur in PD psychosis. They are usually a result of the disease itself, the side effects of medication, and occasional illnesses such as infections or metabolic disorders.

Visual hallucinations often start by a sensation of a presence, described as a shadow in the peripheral vision, which quickly disappears once the patient tends to it. More severe hallucinations may take the form of an animal or person with usually retained insight and are generally not bothersome to the patient.

Management of hallucinations most times begins with exclusion of secondary causes such as underlying infection, metabolic derangement, renal, hepatic or endocrine dysfunction, cancer, stroke, etc. Hallucinations in PD patients can be treated with antipsychotics, such as Clozapine or Quietiapine, without worsening PD symptoms. Clozapine is not the preferred medication due to the frequent blood monitoring for side effects of agranulocytosis. Quietiapine is the medication most frequently used to treat hallucinations. Due to sedative properties, Quetiapine is commonly given before bedtime and can serve as a sleep aid and improve sleep. If hallucinations persist, discontinuation of Selegiline, Amantadine and anticholinergics should be considered, and dopaminergic agents should be reduced if possible. ■

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Fatigue & Sleep Disorders

Joseph Friedman, MD, Director of the Movement Disorders Program at Butler Hospital and Professor and Chief of the Division of Movement Disorders at the Warren Alpert Medical School of Brown University.

Joseph Friedman, MD

Dr. Friedman first presented this topic as a PD ExpertBriefing, available to view online at www.pdf.org/parkinson briefing sleep fatigue. It is also available as a PDF Fact Sheet and is reprinted here with permission of the author and the Parkinson's Disease Foundation.

If you are living with Parkinson disease (PD) and find that you experience fatigue and sleep problems, you are not alone. These are common symptoms of Parkinson disease. Fatigue can occur at any stage of PD. In my research, I found that in a group of 100 people with Parkinson disease, one-third reported fatigue as their worst symptom. It was a bigger problem for these individuals than stiffness, slowness, or walking problems. Other studies have had similar results and have shown that sleep disorders affect about 90 percent of people with Parkinson disease. But doctors often overlook these symptoms when caring for people with PD because the disease is defined by problems with movement like rigidity, stiffness, and tremor. So how can you cope with these symptoms to ensure you feel your best? First, it is important to understand the symptoms and then to employ strategies to ease their impact on your Parkinson disease.

What Is Fatigue?

People who are fatigued are often sleepy, and sleepy people are often fatigued, but fatigue is different than sleepiness. Fatigue is a feeling of being extremely tired, of being either physically or mentally weary. Most people talk about fatigue as a result of some type of exertion – being tired from working, or from thinking – but sometimes it is there all the time.

Fatigue is also a symptom of depression. If a person is depressed, it is important to seek treatment. Although people with Parkinson disease often have both fatigue and depression, they can feel fatigued without being depressed. Most physicians believe that fatigue is a symptom intrinsic to PD, a result of the same brain changes that lead to motor symptoms.

In our recent study, my colleagues and I found that fatigue is a common symptom in the earliest stages of Parkinson disease. The level of fatigue was not found to be related to the severity of motor symptoms, and people who had severe fatigue early in their Parkinson disease tended to stay fatigued.

Treating Fatigue

Researchers have found that medications that help motor symptoms do not necessarily improve fatigue, although, in one study, levodopa was shown to slow the worsening of fatigue. So, is there any therapy that can help fatigue? Unfortunately, research in this area is in its early stages. Two therapies – testosterone replacement and modafinil – were tested, but proved unsuccessful. In a small trial, methylphenidate (Ritalin) was found to be effective, but this and other stimulants have not been approved for treating PD. More studies are needed.

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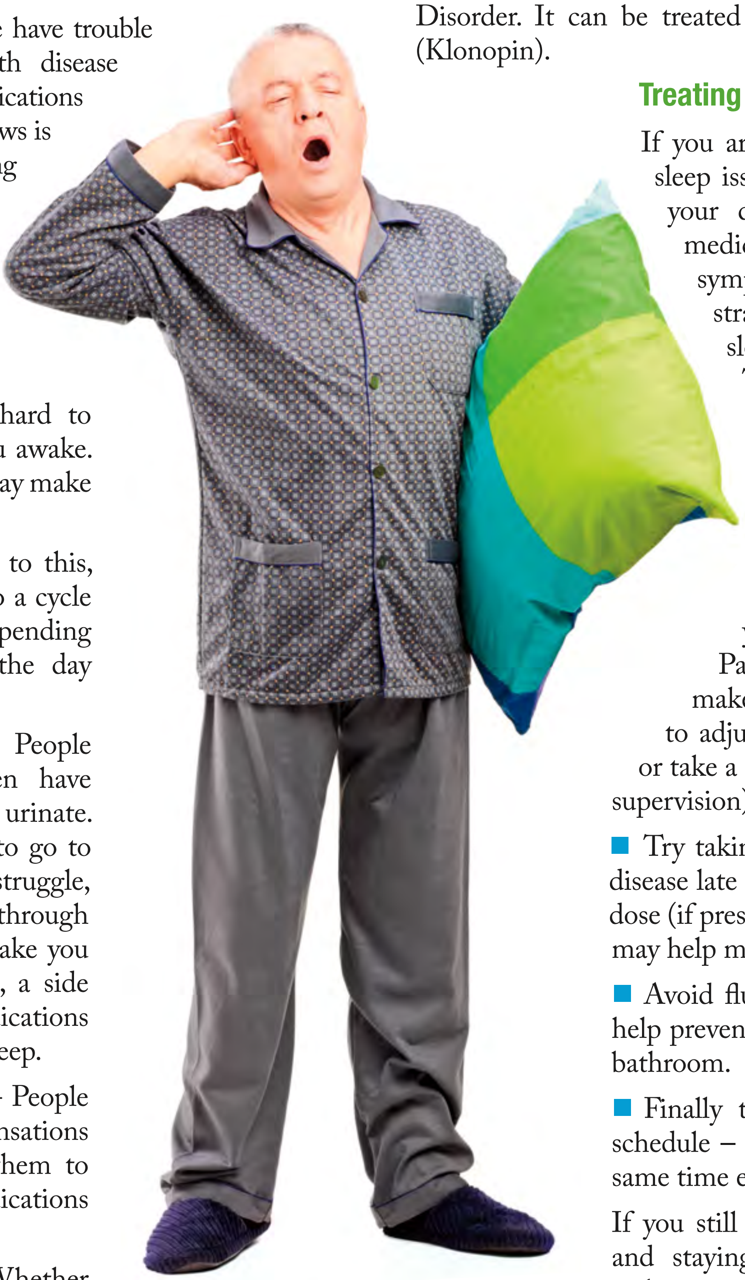
To date, exercise is the best known therapy for fatigue. People with Parkinson disease often say that they are too fatigued to exercise, but paradoxically they feel more energetic afterward. When exercising, you should have reasonable expectations. Start slowly by walking or using an exercise bicycle for five minutes, and build up to 30 minutes a day. There is no downside to exercise, and it is my belief that it will improve fatigue, one's sense of well-being, depression, and sleep quality at night.

Sleep Problems

Most people with Parkinson disease have trouble getting a good night's sleep. Both disease symptoms and anti-Parkinson medications can interfere with sleep. The good news is that effective medications for treating most sleep problems are available. The most common sleep issues for people with Parkinson disease are:



- **Insomnia** - Difficulty getting comfortable, whether from pain or because it is hard to turn over in bed, can keep you awake. Napping during the day also may make it difficult to sleep at night.
- **Inverted sleep cycle** - Related to this, napping frequently can lead to a cycle of staying awake at night and spending more time sleeping during the day than at night.
- **Sleeping through the night** - People with Parkinson disease often have nocturia – a frequent urge to urinate. Getting up during the night to go to the bathroom, which may be a struggle, keeps people from sleeping through the night. Tremor also may wake you up. In addition, vivid dreams, a side effect of levodopa-based medications such as Sinemet, can disturb sleep.
- **Restless Legs Syndrome (RLS)** - People with RLS feel creepy-crawly sensations or discomfort that compels them to move their legs. Several medications are available for treating RLS.
- **Early morning awakening** - Whether it is a habit from old work schedules or because of a very early bedtime, people with Parkinson disease often wake up too early in the morning. If you go to bed at 7 PM, it is going to be hard to stay asleep until 6 or 7 AM the next morning.
- **Sleep apnea** - People with sleep apnea stop breathing for short periods of time. This prevents them from entering the deep restorative stage of sleep. In the general population, sleep apnea is associated with obesity and cigarette smoking. There are several treatments available for sleep apnea.
- **REM sleep disorder** - REM stands for rapid eye movement. This is the stage of sleep when dreams take place. People with REM sleep disorder act out their dreams which sometimes are violent. Among people with Parkinson disease, about one third of men but very few women develop the disorder, which is called REM Behavior Disorder. It can be treated with the drug clonazepam (Klonopin).

Treating Sleep Problems

If you are experiencing any of these sleep issues, it is best to speak with your doctor to see if there are medications available for your symptoms. There are also several strategies that may help you to sleep more soundly at night. These include:

- First, try to increase your activity and avoid napping during the day. Getting exercise will help you sleep, and it has long-term benefits for your health. Because anti-Parkinson medications can make you sleepy, you may need to adjust your daytime medication, or take a stimulant (with your doctor's supervision) in order to stay awake.
- Try taking medication for Parkinson disease late in the day, or taking an extra dose (if prescribed by your doctor) as this may help make you sleepy at night.
- Avoid fluids after dinner, which will help prevent having to get up to use the bathroom.
- Finally try to keep a regular sleep schedule – go to bed and get up at the same time each day.

If you still have trouble going to sleep and staying asleep after trying these techniques, you may want to consider the possibility of taking a sleep medication recommended by your doctor.

Conclusions

If you experience any of these symptoms, it is important to realize that they could be a part of your Parkinson disease and that there are ways to address them. By ensuring you are well rested, you will feel your best. ■

American Parkinson's

OPTIMISM

The Optimism Club recognizes individuals or businesses who contribute $500 or more in donation and/or sponsorship of an event from January 1 through December 31, 2013.

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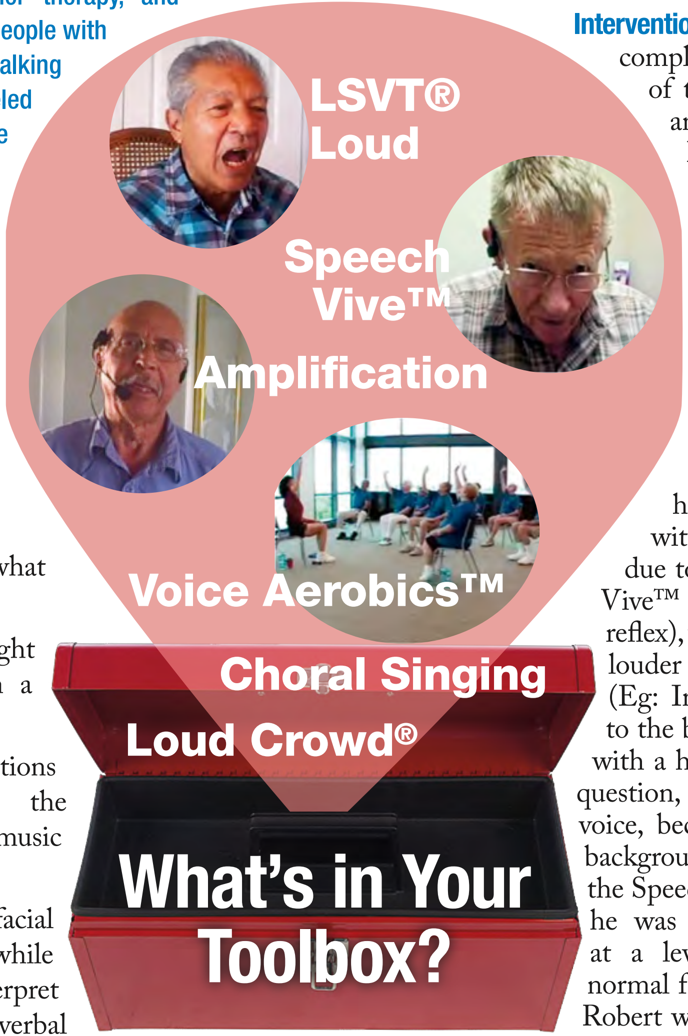
Enhancing Communication for People with Parkinson Disease: What's in Your Toolbox?


Mary Spremulli

Mary Spremulli, MA, CCC-SLP, Voice Aerobics

When better communication is a goal for individuals with Parkinson disease, a multi-modality approach should be used, which considers an individual's abilities, including memory for instructions, stage of disease, history of prior therapy, and individual goals. When people with Parkinson disease have difficulty with walking and balance, many use canes, wheeled walkers, or wheelchairs depending on the setting or their function on any given day. Similarly, if an individual is having difficulty communicating with others at home or in the community because of changes to speech and voice, and/or cognition, they too may benefit from having access to a variety of tools that can support or enhance communication.



Being a good communicator is more than just having a voice that is loud enough to be heard. It also involves:

- being able to hear and process what another person is saying.
- being able to formulate a thought quickly enough to respond in a timely manner.
- being able to tolerate interruptions and other distractions in the environment like a television or music playing in the background.
- being able to incorporate facial expressions and body language while speaking, and correctly interpret facial expression and other non-verbal aspects of communication like tone of voice in another speaker.

When one looks at the list above, it is no surprise that some individuals with Parkinson disease may eventually have a breakdown in some or all of the components of communication. So what is available to help?

I will use a recent patient example as a way of illustrating how a multi-modality approach might be of benefit.

Patient: Robert, a 74-year old male, retired airline pilot with a diagnosis of Parkinson disease approximately four years ago. He is married and has children that live out of state. He attends my weekly Voice Aerobics ™ class, and he requested an individual consultation because of changes in his speech and voice that have caused him to speak very softly. He also has fairly severe head drop, and although he can bring his head upright briefly, his usual position is with his head flexed resulting in poor or no eye contact with the listener. He underwent formal speech therapy (LSVT®) three years ago, and although he feels it helped at the time, gradually, over the last three years, his voice has declined. Some days he walks with a cane, and at other times he uses a wheeled walker for balance.

Intervention/s: Since Robert had previously completed the **LSVT®**, he was aware of the principles of that treatment and the daily exercises it entails. Rather than completing 16 sessions of individual treatment, he elected to participate in a weekly, small group session with three other individuals who had also completed LSVT® in the past, but now require a "refresher" course. Robert also had an opportunity to trial the **Speech Vive™**, a new device intervention that has been developed for persons with hypophonia (weak/soft voice) due to Parkinson disease. The Speech Vive™ acts upon a reflex (Lombard reflex), which causes most of us to speak louder when there is background noise. (Eg: Imagine that you were listening to the ball game on your portable radio with a headset. If your wife asked you a question, you might answer her in a loud voice, because you are talking over the background noise of the ballgame.) When the Speech Vive™ was placed on Robert, he was instantly louder and speaking at a level that would be considered normal for conversation in a quiet room. Robert wore the device at home for four weeks, and both he and his wife report an improvement in loudness, and even friends have commented that Robert is speaking louder on the phone. Even with a louder voice, however, Robert's head drop still leaves him at a disadvantage. Since others cannot make contact with his eyes, it is difficult to know if he is listening or even has something to say. So additional strategies were discussed for how he could signal to people that he was listening to the conversation and/or that he had something to say.

Finally, a **personal voice amplifier** was suggested for Robert which he could use in a group setting. The amplifier gave instant loudness, and because the volume could be regulated, even in a large room with 20 people or more, everyone was able to hear and understand what Robert had to say. Amplification was recommended as a great option when he needed power for his

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voice at social gatherings, at home, or anywhere, or at any time of day when meds wore off, and voice use was more difficult.

In addition to all of the options mentioned, some people are lucky enough to be able to participate in community based programs, and these may include programs such as Voice Aerobics™, the Loud Crowd® and choral singing. Group programs (post-therapy) can also be a great way for anyone to continue to use and strengthen their voice in a fun atmosphere with others. ■

$50,000 Gift Received

"Why wait until you are no longer here to appreciate the value of your gift and the support it provides with much needed resources?" That was the question Jo Oertli posed recently. "Parkinson disease has had a personal and devastating effect on my husband's life, but also on mine and our children's lives, as I'm sure it has had on you and your family." While only one family member may actually have the disease, the entire family shares the weighty burden of its impact, especially those family members who become caregivers. "Twenty years ago my husband, Fred, was diagnosed with Parkinson disease. Fred and I are grateful to have the opportunity to financially support the research Dr. Perlmutter and his fine staff are doing. As a result of their dedication and perseverance, perhaps one day, they and others will discover the causes and a cure for this dreaded disease.

I sincerely encourage you to participate through your support, as your assistance, large and small, is so greatly needed to achieve such a victory." We thank Jo and Fred Oertli on behalf of every person whose life will be touched by their generosity this year and beyond. This gift has enabled Dr. Perlmutter to hire another fellow beginning July 1, 2014, who will spend his life taking care of people with Parkinson disease and doing research to find the cure. Dr. Perlmutter reminded us that this fellowship position will provide another skilled clinician and scientist specializing in the field of Movement Disorders. Together we will continue to accomplish much more in 2014, and we thank Fred and Jo Oertli for their most generous gift to the APDA Advanced Center for Parkinson Research at Washington University School of Medicine. ■

Dr. Joel Perlmutter, Fred and Jo Oertli

Parkinson Disease and Wearing Off (Clinical Trial)

Dr. Susan Criswell at Washington University School of Medicine is participating in a research study investigating a medication for Parkinson disease. The purpose of this study is to test the safety and effect of an investigational study drug, istradefylline, in patients who have been optimally or maximally treated with levodopa/carbidopa therapy. KW-6002 (istradefylline) is an investigational drug which means that it is not approved for use in the United States of America (USA) by the Food and Drug Administration (FDA) and therefore has not been marketed in the U.S.

This study will test the safety and effectiveness of istradefylline to determine if it can reduce OFF time for Parkinson disease patients with motor fluctuations and a history of dyskinesia (involuntary jerking/twisting). We want to find out what effects, good and/or bad, it has on you and your Parkinson disease. The study is sponsored by Kyowa Hakko Kirin Pharma, Inc. (KKP).

To qualify for this study, the participant must:

- Be 30 years old or older
- Be diagnosed with idiopathic Parkinson disease
- Be taking levodopa for at least one year
- Be experiencing wearing OFF of your PD medications
- Have no history of Deep Brain Stimulation (DBS)
- Smoke fewer than five cigarettes per day (if smoke at all)
- Satisfy additional criteria that apply

Participation will last approximately 18 weeks and includes seven office visits. Compensation is provided. For more information, please contact Karen McDonell at 314-747-0514 or **mcdonellk@neuro.wustl.edu**. ■

Tributes & Donations 10/26/13 – 12/31/13

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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Gail & Larry Glenn

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Steven Horn

Carl Chutz
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Lowell & Sondra Crow

Dr. Joel Perlmutter's PEP Presentation
Debbie Guyer
Mary Perisho

Dale & Norma Plank's 50th Anniversary
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Terri & Bill Taylor's Birthdays
Roselynn Gad

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We thank all of our donors, big and small, and hope you will continue your support in 2014.

Programs & Services Offered by the Greater St. Louis APDA

Dance for PD internationally-acclaimed dance program developed by Mark Morris Dance group/Brooklyn Parkinson Group will be offered on a weekly basis in cooperation with COCA. Participants are empowered to explore movement and music in ways that are refreshing, enjoyable, stimulating and creative. Classes will begin in the spring. Those interested in participating in this new dance class that engages the mind, body and spirit should contact the Center (314-362-3299) for further information and start dates and times.

DVDs Exercise DVDs and recordings of the Patient Educational Programs (PEP) presented by the Chapter are available for purchase. Note that *The Parkinson Journey* is still being offered at no cost to Missouri and southern Illinois patients, family members and professional staff.

Emergency Response System
Participants who stay home alone can wear a push button necklace which summons emergency help when activated. The Greater St. Louis Chapter of the APDA offers financial assistance to people with PD who are unable to afford the program. Income guidelines apply.

Exercise Special weekly classes for people with Parkinson disease that focus on improving balance, posture, functional mobility and self-help skills. Exercise classes are held throughout Missouri, with the majority of them in the Greater St. Louis area. People with PD can attend one class per week at no charge, or for $20/month, they can attend as many classes as they want. Types of exercise classes include: aquatic, Tai Chi, and chair side.

Fundraisers The Chapter raises money through tributes, private donations and special events to support patient services, PD research and the Resource Center. For 2014, we will have three major fundraisers. The Greater St. Louis APDA has been chosen to participate in the 2014 GO! St. Louis Marathon & Family Fitness weekend to be held April 5 and 6. Our annual Golf Tournament in memory of Jack Buck will be held on Monday, May 19, at Algonquin Golf Club. The annual “Off the Rack” fashion show and luncheon will be held on Monday, October 13, at the Sheraton Westport Lakeside Chalet.

Literature Literature in the form of single booklets and brochures are available from our APDA Parkinson Resource Center. Welcome packets are mailed out to those who contact our office and include a LiNK newsletter, handbook, brochures and a literature request form. This request form is also available online on our website, www.stlapda.org.

Loud Crowd This group incorporates practice and role play to preserve skills that people with PD have worked hard to regain sometimes through the Lee Silverman Voice Technique (LSVT), though the LSVT is not a requirement.

Newsletter The Chapter publishes a quarterly newsletter, the LiNK, that is mailed to over 9,000 households and doctors’ offices. Included in the newsletter are PD-related articles, a listing of tributes and donations, and updated listings of support group and exercise classes in Missouri and southern Illinois and a tribute envelope.

Optimism Events An optimism event is a great way for an individual or company to fundraise on behalf of the Greater St. Louis APDA. Examples of these include a jeans day at your place of employment, ticket sales from a local theater production, proceeds from the sale of t-shirts, dining at restaurants, and a bowling party for APDA.

PD 101 Newly diagnosed people with PD meet one-on-one with Debbie Guyer, Executive Director of the Greater St. Louis APDA, for an informational session that includes a Power Point presentation and opportunity to ask questions specific to their diagnosis.

Respite Care This program is for the caregiver to get some “time out” either through in-home care or adult day care. A shared cost program helps subsidize the cost for non-medical care of a person with PD in their home. Income as well as other criteria determine qualification.

Role Reversal For caregivers who find it hard to manage their new role and chores around the house, the Chapter, along with the assistance of Washington University occupational therapy students, will be starting a series of classes to help caregivers with role reversal this spring. Classes may include money management, cooking, sewing, car maintenance, hair care, home repairs, etc.

Support Groups Monthly support groups offer people with PD and their caregivers the opportunity to exchange thoughts and share concerns and solutions to problems. The Greater St. Louis APDA sponsors over 30 support groups throughout Missouri and southern Illinois.

Tremble Clefs This is a nation-wide program for people with Parkinson disease, their family members and care partners. The goal of this group is to be a participant-led, musical experience. Through vocal exercises, singing as a group, and playing instruments, members will come together and bond over a shared joy of making music. Tremble Clefs began on January 14. Registration required.

Tributes Tributes are a wonderful way to acknowledge the memory of a loved one as well as honor those who mean so much to you. Tribute envelopes can be obtained from the Resource Center or contributions can be made directly on the Greater St. Louis APDA website www.stlapda.org.

Wellness Classes A series of six-week classes helps people with PD and their family members develop skills and confidence in managing everyday activities and relationships that can be challenging when living with Parkinson disease. Registration required as class is limited to six couples per session. ■

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	2:00 PM	Gayle Truesdell	636-923-2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street, Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck 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	314-306-4516
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	573-201-7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	**2nd Thursday**	**2:00 PM**	**Randi Newsom, RN, BSN**	**417-820-3157**

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Missouri Support Group Calendar

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573-543-2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660-357-2283 660-485-6558
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314-713-4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, 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

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
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.	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

Coming Soon!

Dance for PD

and

EXERCISE CLASS

at

Friendship Village in
Chesterfield

KEEP MOVING

Week At-A-Glance

EXERCISE EVERY DAY OF THE WEEK

Monday	Tuesday	Wednesday	Thursday	Friday
Exercise 10 AM Chesterfield	Exercise 10 AM Florissant	Tai Chi 10 AM Chesterfield	Exercise 10 AM Florissant	Tai Chi 11:30 AM Chesterfield
Exercise 11:30 AM South County	Exercise 11 AM St. Charles	Exercise 2 PM Clayton	Exercise 1 PM Kirkwood	Exercise 2 PM Clayton
Exercise 1:30 PM Chesterfield	Aquatics 1 PM Creve Coeur		Aquatics 2 PM St. Charles	

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. Check our website, www.stlapda.org, or call to find 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	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	1:30 PM	Susan Mayer, MHSPT	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Winter Session Jan. 6-Mar. 14 **Spring Session Apr. 7-Jun. 13**	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
Kirkwood	**St. Louis**	**RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear**	**Thursday Starting Feb. 6**	**1:00 PM**	**Brandon Takacs**	**618-971-5477**
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.	Winter Session Jan. 6-Mar. 14 **Spring Session Apr. 7-Jun. 13**	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

TO EASE THE BURDEN
TO FIND THE CURE
American Parkinson Disease Association

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

facebook

Check out our 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!

Washington University School of Medicine
American Parkinson Disease Association
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St. Louis, MO 63110
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Join the APDA Team of Runners and Walkers at the 2014 GO! St. Louis Marathon & Family Fitness Weekend

We hope you and/or your family will consider joining the APDA team as a participant for the 2014 GO! St. Louis Marathon & Family Fitness Weekend on April 5 and 6. In addition, we are looking for sponsors to join the individuals and families who are fundraising for the APDA by participating in one of the many events taking place. Our goal is to raise at least $10,000 this first year as a charity of GO! St. Louis. This event will raise awareness of Parkinson disease as well as raise funds for research and the APDA Information and Referral Center network.

Each year, the GO! Marathon weekend attracts 25,000 participants and 50,000 spectators. The events on Saturday, April 5 in Forest Park include:

- **5K Walk/Run..............................8:00 AM**
- **Children's Fun Runs ....10:45 AM (various ages)**
- **Mature Mile ....11:15 AM (adults 60+ walking one mile)**

The Marathon, Half Marathon, Marathon Relay (4 person) events will be held on Sunday, April 6, in Downtown St. Louis. They will start at 7:00 AM and conclude at 1:15 PM.

In order to join the APDA team or to volunteer on Sunday, please contact Michelle Brooks at 314-362-3299 or brooksmi@neuro.wustl.edu. After completing a commitment agreement, participants will be given a charity code to use when registering online. We encourage you or your friends and family to sign up early as some events do sell out. To see who has joined our team, how much we have raised to date, or contribute to our fundraiser, visit our team page at: www.crowdrise.com/teamamericanparkinson2014. We hope to see you in April! ■

2014
Save the Date!

February 2
Deep Brain Stimulation (DBS) Parkinson Education Program (PEP) (see www.stlapda.org)

April 5-6
2014 GO! St. Louis Marathon & Family Fitness Weekend

May 19
APDA Annual Golf Tournament in memory of Jack Buck.

October 13
"Off the Rack" Luncheon and Fashion Show