LiNK St. Louis APDA

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

Mission

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

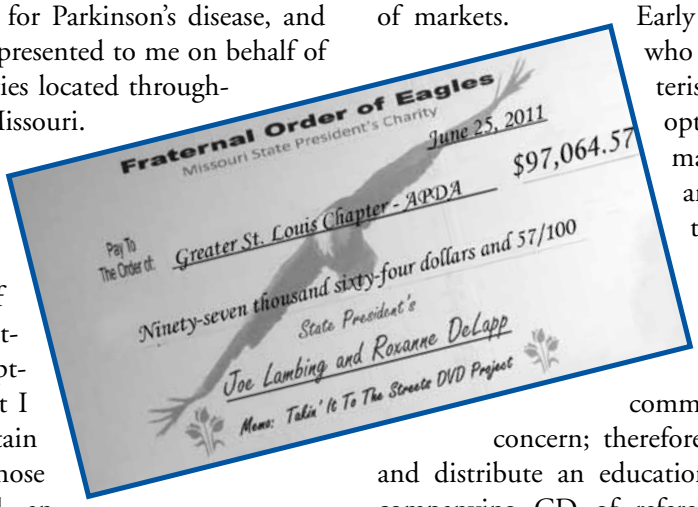
In This Issue

Fraternal Order of Eagles Are Takin' It to the Streets

Award $100,000 Grant to the St. Louis Chapter of the APDA

Deborah Guyer, M.A., Executive Director, Greater St. Louis Chapter APDA

On Saturday, June 25, I traveled to Jefferson City with my husband to attend the Fraternal Order of Eagles State Convention and banquet at the Aeries in Jefferson City. It was the culmination of a year of campaigning to raise funds for Parkinson's disease, and a check would be presented to me on behalf of all the various Aeries located throughout the state of Missouri.



I'm not certain which camera was aimed in the direction of those at the front of the room presenting and/or accepting this check, but I am relatively certain that no matter whose face was captured, an expression of astonishment and amazement and pride would have been caught when the dollar amount of what they had collected was revealed as the ceremonial check was unveiled. The St. Louis Chapter of the American Parkinson Disease Association is the recipient of close to $100,000 which will be used to produce and distribute new materials in the DVD slated to be filmed this year, dealing with the most current information on Parkinson's disease, freezing, Deep Brain Stimulation, benefits of exercise, etc. We are now poised to begin this undertaking and look forward to not only sharing it with residents of Missouri but also with our neighbors in surrounding states and throughout the country.

The St. Louis Chapter's vision is to expand significantly its patient services and education programs to better meet growing and unmet needs. This grant will enable us to achieve our goal of "easing the burden" by furthering education about Parkinson's disease in these types of markets. Early diagnosed patients who learn about characteristics and treatment options can better manage symptoms and greatly enhance the quality of their own lives. Inadequate access to quality information in rural communities is a special concern; therefore, we will produce and distribute an educational DVD with accompanying CD of reference material. The DVD will be divided into chapters to inform medical personnel as well as frequently asked questions for patients and families. There will be no charge for this instructional media set, and it will be mailed to 3,500 underserved locations. In response to community needs, the proposed expansion is both geographical to underserved out-state areas, as well as vertical to encompass physicians, professional caregivers, and senior living facilities.

Parkinson's disease is a chronic, progressive, neurodegenerative disease. There are no socioeconomic boundaries, no known causes, no diagnostic tests, and no cure. PD can linger for decades. Early non-motor symptoms go unno-

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Making A Difference

Ambassadors for Increasing Awareness of Parkinson's Disease and Resources

Deborah Guyer, M.A., Executive Director, Greater St. Louis Chapter APDA

You, too, can make a difference. Each and every one of you reading this newsletter can make a difference. Are you up to the challenge? And it doesn't even require writing a check (although we never turn those away). You don't have to be wealthy, but you can still make a huge difference. Let me share with you some stories about people making a difference.

There is never a donation too small. We have a special donor, Char Ann, in Blue Ball, PA, who sends a $1 bill hidden within newspaper coupons she clips every week and sometimes twice a week. So monetary donations of any size are gladly accepted and always appreciated, no matter how many zeros precede the decimal point.

We, also, have an artist, Mark, with PD who has his artwork displayed on consignment at various studios around town, and he donates the proceeds of his sales (minus his material costs) to APDA as his way of contributing to our mission.

Recently, we have received several phone calls from people wanting to have their own local fundraisers. For example, the Vermillion family held a fish fry and bean bag toss for family and friends in their rural community, raising $1,551 for DBS research. I also heard from the wife of a musician who has PD. His friends wish to hold a benefit for their fellow musician who played in various bands from the 60s through the mid 2000s. And, in addition, Tommy from Columbia called to tell us that he wants to memorialize his dad by fundraising and hosting a tractor pull in October.

Also, there are individuals who donate gift cards/certificates they've received from local restaurants and businesses for use in our Tastes of Our Town buffet at our fashion show auction. There is also the business owner who wants to become a new sponsor of our fashion show.

Another way patients and family members have helped get out the news about Parkinson's disease is by spreading awareness. One man asked his church to please include information about Parkinson's disease in its bulletin, including how to contact the Greater St. Louis APDA for resources. Now many other members of the church will benefit from having this information at their fingertips. Also, there was a patient who went to her internist and neurologist, and she showed them the welcome packet of information that we send out to new patients. She offered to help supply their waiting rooms with this information. Now all patients have access to Parkinson's literature and the Greater St. Louis APDA!

Awareness is the key to funding and finding a cure for this devastating disease. We hope you will consider planned giving. There are so many different options, big and small, for leaving a legacy.

We're counting on your generosity and creativity. You are not alone. There are over 130,000 newly diagnosed cases in this country every year. Let's make sure we can help someone who doesn't know much about this disease or the resources available. We're the best kept secret, and you can help spread the word and increase awareness. You, too, can make a difference! ■

Roth IRA Conversion – Not Only for the Wealthy!

Brian Hantsbarger, Conner Ash, P.C., APDA Board Treasurer

Almost everyone has heard of the Roth IRA. It was established approximately 14 years ago. The basic rule is that contributions to this retirement vehicle are non-deductible, but qualified distributions from the account are tax-free. Starting in 2010, anyone can convert a traditional IRA to a Roth IRA. Any amount that you convert from a traditional IRA to a Roth IRA will be taxable in the year that you convert.

The rules surrounding the Roth IRA are complex, and there are many exceptions to the general rules. I will not attempt to itemize all of the rules and exceptions in this article. Also, I will not be discussing the annual contribution rules. My purpose is to give you a summary of when a Roth conversion may be beneficial and should be considered.

The primary benefits of the Roth IRA for most individuals are:

- 100% of the growth is tax-exempt. For example, if you put $100,000 in a Roth and it increases in value to $200,000 at the time you withdraw the funds, none of the $200,000 is taxable
- No required minimum distributions at the age of 70½ - unlike a traditional IRA.

You do not have to be wealthy to benefit from a Roth conversion. The basic rule of thumb is if your income tax rate is lower at the time you convert to a Roth than when you take distributions from the Roth, it may be a good idea to convert. If you will be at the same tax bracket both times, then it may make little tax difference. This is true no matter what the stock market does from the time you convert to the time you take the distributions.

Following is a general list of situations where a Roth conversion should be considered. However, you must keep in mind that all conversions should be reviewed with your professional advisors as various factors need to be considered and each situation is unique:

- If you have a year with unusually high medical bills that reduces your income to a low tax bracket.
- If you and your spouse are in a fairly low tax bracket and both of you are in poor health, you may want to convert some of your IRA to a Roth if your children will be inheriting the regular IRA shortly and they are in a higher tax bracket.
- If your current tax return status is *married filing joint* and you anticipate a change to single status due to your spouse's poor health.
- If your minimum required distributions each year are causing your social security income to be included in your taxable income.
- If you are in a lower tax bracket now than you will be when you retire – especially if you do not need the amount converted to meet your annual living expenses.
- If you are in same tax bracket now as you will be when you retire but you want to convert to provide your children with tax-free money after your death. This really works well if you have investment money outside of your IRAs to pay for the taxes due on the conversion.
- If you and your spouse will not need the amount you convert during both of your lifetimes, Roths can be especially advantageous. This is because Roth IRAs are not subject to the required minimum distribution rules. So the Roth IRA can accumulate tax-free for both of your lifetimes, and your beneficiaries can then take distributions over their lifetimes.
- If you have made non-deductible IRA contributions in prior years, you may wish to convert even if you will be in a lower tax bracket in your retirement years.

Even with the best of planning, a Roth conversion might prove to be a very bad decision because of developments that occur after the conversion. For instance, $100,000 could be converted to a Roth on July 31, 2011, and by December 31, 2011, the market has crashed and the account is only worth $70,000. If nothing is done, you will still owe taxes on the $100,000. Fortunately, there is a way to undo a Roth IRA conversion. It's called a "recharacterization." Because of this opportunity to "undo" a Roth conversion, the risk involved in making a mistake is greatly reduced.

Given the right set of circumstances, a Roth conversion can provide a wonderful benefit over a number of years. This can be the case whether someone has $50,000 or $5,000,000 in their IRAs. However, each conversion is unique because each family situation is unique, especially when Parkinson disease is involved. Therefore, each individual must examine his personal financial circumstances to determine whether the advantages outweigh the disadvantages. ■

We need your help

for a new study run by Joel Perlmutter, MD at Washington University to investigate thinking problems in PD. The study involves thinking and memory games, lumbar puncture, MRI, PET scanning, and brain donation at the time of your death. It pays $300 for time and participation. We are looking for people with Idiopathic PD, no matter if they have thinking and memory problems or not; as well as normal controls without PD or thinking problems.

For more information, please contact Johanna Hartlein at 314-362-0420 or johanna@npg.wustl.edu

Cognitive Issues in Parkinson's Disease

Jennifer G. Goldman, M.D., M.S.
Assistant Professor, Section of Parkinson Disease and Movement Disorders,
Department of Neurological Sciences, Rush University Medical Center, Chicago, IL

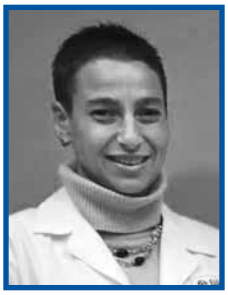
In this article, Dr. Goldman will focus on cognitive issues in PD. This article was prompted by her Parkinson Education Program on April 29, 2011 in St. Louis, Missouri.

It is now recognized that Parkinson's disease (PD) is much more than a motor disorder. Tremor, slowness, stiffness, and walking trouble are only part of the picture. Non-motor symptoms in PD are common and affect cognition, behavior, sleep, autonomic function, and sensory function. Studies of PD patients followed over many years reveal that non-motor symptoms become even more important as PD advances. Increased recognition and improved treatments for these non-motor symptoms are greatly needed.

Cognition

First, what is cognition? Cognition is a general term that refers to the mental abilities that we use to process information and apply knowledge. These mental processes allow us to perform daily functions such as paying attention, solving problems, and remembering where items are and how to do certain tasks. When people typically talk about cognition, they often focus on "memory," but "memory" is only one aspect of cognition. Rather, in the study of cognition, we talk about "cognitive domains" which reflect different types of cognitive processes and are described in detail below.

1 **Attention and working memory:** Attention is the ability to selectively focus on a particular aspect of one's environment, often while ignoring competing stimuli. In PD, people may find it difficult to concentrate on a conversation or reading a book. It may be challenging to talk to someone while walking and maintaining balance. Working memory refers to the memory process of temporarily storing information in one's mind and manipulating it over a short period. Mental arithmetic is one example of working memory function. These cognitive processes are often linked to alertness. Sleepiness and sedating medications can impair attention and working memory function. These cognitive processes involve the frontal and parietal lobes in the brain. Working memory also involves the basal ganglia and dorsolateral prefrontal cortex, regions affected in PD.



2 **Executive function:** Executive function includes the ability to plan, organize, initiate, and regulate goal-directed behavior. One can think of the "CEO" (chief executive officer) of a company and the many tasks involved in directing the organization. These activities may include multitasking, solving problems, starting new tasks, and switching tasks. Executive function involves the prefrontal cortex of the brain and the dopamine system, which are affected in PD. Executive dysfunction is one of the most common cognitive changes reported in PD.

3 **Memory:** In general, the concept of memory invokes learning and remembering information. Memory, however, can be classified into different processes and types. For instance, there is immediate (seconds-minutes), short-term (minutes-days), and long-term memory (days-years). There also is memory for facts, concepts, or events (called declarative memory) and memory for how to do certain tasks like tie our shoes or ride a bicycle (called procedural memory) as well as working memory (described earlier). Declarative memory typically involves the hippocampus or temporal lobe of the brain, whereas procedural memory often involves the frontal areas and basal ganglia. People with PD may have trouble recalling information, but in general, memory is less impaired in PD compared to Alzheimer's disease. In PD, people frequently recall information more readily when given cues or choices. This helps the person to retrieve information from the brain's memory storage. Long-term memory function typically remains intact in PD.

4 **Language:** Language abilities include naming objects, generating words, comprehension, and verbal concepts. The most common language problem in PD is finding the "right" words. People with PD also tend to speak less overall (in addition to softer voice) and use simpler speech. This can be an area of frustration for both the patient and caregiver because verbal communication is such an important part of human behavior.

5 **Visuospatial function:** These abilities tell us where things are around us in space, give us a spatial map of our environment, and involve our sense of direction. Visuospatial functions allow us to estimate distance and depth perception, use mental imagery, copy drawings, or construct objects or shapes. Examples include being able to give someone directions to your house by tracing the route in your mind, avoiding obstacles in one's path, and putting together a puzzle. These abilities rely on the parietal lobe of the brain.

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Cognitive Issues in PD

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Cognitive evaluation

There are several ways to assess cognition in the clinical or research setting. Reports from the patient and the patient's caregiver, spouse, or friend are important sources of information. The physician may ask questions about cognitive function, whether the cognitive problems represent a change from prior functioning, and how it impacts activities of daily living or work. The physician may perform short tests of thinking and memory, but generally the "gold standard" is more comprehensive, formal testing by a neuropsychologist. These evaluations include multiple tests to assess different cognitive domains. Some of the tests require oral answers, while others use a pencil and paper. This evaluation may range from about 45 minutes to several hours.

Cognitive changes in PD

Cognitive symptoms in PD are common, though not every person experiences them. In some people with PD, the cognitive changes are mild. In others, however, cognitive deficits may become more severe and impact daily functioning. Similar to slowness of movement (or bradykinesia), people with PD often report slower thinking and information processing (termed "bradyphrenia"). Attention and working memory, executive function, and visuospatial function are the most frequently affected cognitive domains in PD.

Cognitive deficits that are mild and do not impair one's ability to carry out activities of daily living have been termed "mild cognitive impairment." Studies estimate that mild cognitive impairment occurs in about 20-50% of patients with PD. We now recognize that mild cognitive changes may be present at the time of PD diagnosis or even early in the course of PD. They may or may not be noticeable to the person. They may or may not affect work or activities, depending on the demands of specific tasks and work situations.

Dementia refers to a syndrome in which patients have problems in more than one cognitive domain, and the cognitive problems significantly impair everyday life functioning. About 40% of PD patients develop dementia. Dementia in PD typically develops many years after the initial onset of PD and is more common with advanced disease. When dementia develops before or at the same time as the PD motor symptoms, patients are often given the diagnosis of dementia with Lewy bodies. Many physicians and researchers, however, consider PD dementia and dementia with Lewy bodies to represent related disorders and fall under an umbrella term of "Lewy body disorders."

Other reasons for cognitive symptoms

Besides PD, there are other important causes of cognitive dysfunction to keep in mind. Medical illnesses such as thyroid disease or vitamin B12 deficiency can cause cognitive symptoms. Urinary tract infections or pneumonia can acutely cause confusion or hallucinations. In these settings, the cognitive symptoms are generally reversible after the infection or medical condition is treated. One should be aware that some medications for pain or bladder problems may cause sedation/sleepiness or confusion, and, thereby, impair cognitive function.

Overall, there are variable effects of dopaminergic medications (levodopa, dopamine agonists, MAO-B inhibitors) on PD cognition. Some studies report improved alertness, working memory, and planning abilities. Other studies find no effect of dopaminergic medications on PD cognition, and some report increased cognitive symptoms or increased sleepiness. Elderly patients do not tolerate dopamine agonists and anticholinergics as well as younger people and are more susceptible to confusion or hallucinations. It is important to check with one's physician regarding potential drug interactions or side effects. In addition, hearing loss or vision impairment can be a cause of cognitive problems. If one cannot adequately see or hear the information well enough to process it, it can be difficult to learn, remember, and retrieve it. Cognitive function also can be affected by poor nighttime sleep and excessive daytime sleepiness. Depression and anxiety may mimic cognitive symptoms. Lastly, head trauma, seizures, strokes, or "mini-strokes" may be other reasons for cognitive deficits.

Causes of cognitive impairment in PD

The exact causes of cognitive impairment or dementia in PD are not fully understood. There may be changes in the neurochemical signals that the brain uses to pass along information to different regions of the brain. Besides dopamine, the neurochemical signals (or neurotransmitters) - acetylcholine, serotonin, and norepinephrine - are especially important for cognition, memory, attention, and mood. In autopsy studies, Lewy bodies, abnormal protein accumulations, have been found in neurons in brain regions responsible for cognitive processes. Other causes include co-existing strokes or "mini-strokes" or Alzheimer's disease pathology.

Management strategies

Management of cognitive impairment in PD depends on the timing and degree of cognitive dysfunction. For example, if cognitive problems develop abruptly, the physician may first search for an infection, new neurological problem (such as a stroke), or newly prescribed medication. If the cognitive problems gradually develop, the evaluation may be different, and examination by a neurologist, neuropsychologist, or specialist in cognition may be helpful.

Medications used to treat dementia in PD have been based on FDA-approved treatments for Alzheimer's disease, even though these are different diseases. The medications work on the cholinergic system in the brain (a neurochemical involved in attention and memory). Medications in this group include donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne). To date, only

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Cognitive Issues in PD

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rivastigmine (Exelon) is FDA-approved for the treatment of dementia in PD. The cognitive effects of these medications in clinical research studies have been modest, but should be discussed on an individual basis with one's physician. Side effects include nausea, diarrhea, and in some, worsened tremor. Memantine (Namenda) is another medication that has FDA-approval for Alzheimer's disease but requires further study in PD dementia. At present, these medications have not been studied in PD patients with mild cognitive impairment.

There are also non-medication strategies for treating PD cognitive impairment. The goals of these strategies are to help patients with cognitive tasks, communication, and daily activities; improve quality of life, and address safety concerns. Pill reminders, clock alarms, and timers are useful ways to help patients remember to take their medications. Executive function strategies use step-by-step approaches to break down activities into simple steps, tools such as making "to do" checklists and daily planners and alarms to keep track of events and time. Maintaining a regular routine for daily activities and exercise is important. Household items such as utensils, glasses, and keys should be kept in the same place all the time, and drawers can be labeled. Patients may respond better when given choices, cues, or yes-no answers, particularly if word-finding difficulties or slowed thinking is present.

Just like physical exercise, mental "exercise" is important for cognition in PD as well as successful aging. Although the exact mechanism is unknown, scientific studies suggest that rats housed in "enriched environments" that have toys and interesting objects show increased brain growth and better capacity for learning than those kept in "boring" environments. This leads to the concept of "use it or lose it" for cognition. Mental activities can include doing puzzles, playing cards or other games, reading a book, going to lectures or concerts, or learning a new activity. These can be coupled with physical exercise such as learning new dance steps or yoga positions. Just like with physical exercise, there is no single "right" mental exercise. Social interactions are an important piece of mental stimulation. Many of these activities can be done with friends or family members. It is important for patients and caregivers alike not to get frustrated when cognitive problems, decreased initiation of activities, or communication problems are present. Patience is key.

While it is not always an easy decision to stop driving, this is an important safety issue to address. Driving involves many different cognitive processes including attention, executive function, visuospatial abilities, and processing speed plus motor demands. Some occupational therapy departments offer simulated driving tests or on-the-road tests that can help physicians and families make decisions about driving abilities. For patients with more advanced dementia, adult day care programs and group activities in the nursing home can enhance social interaction. Social workers can be a valuable asset to help the patient and caregiver deal with stressors and frustrations. ■

Fraternal Order of Eagles

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ticed for years. Later movement problems may consist of tremor, bradykinesia, rigidity, impaired balance, speech changes, and dementia. There are far too many anecdotes about misdiagnoses, medication errors, and deficiencies in professional care. Early and accurate diagnosis, proper treatment, and informed patients can delay the debilitating aspects, as most symptoms can be initially managed successfully with medication and therapies to improve quality of life.

To this end, we will educate family practice physicians as well as neurologists; staff in facilities where people with Parkinson's disease reside (skilled nursing facilities, assisted living and extended care facilities, independent living centers); and patients and their family members about current knowledge concerning Parkinson's disease which impacts more than 130,000 newly diagnosed cases in this country annually. We will make certain that these DVDs are available in libraries and facilities, and we will encourage physicians to view this up-to-date educational information by offering continuing education credits through Washington University. An introduction about Parkinson's disease and frequently asked questions will be utilized. Incidence and prevalence, non-motor and cognitive aspects, treatment options (medicine, exercise and deep brain stimulation), symptom management, caregiver hints and resources, professional patient care and personal experiences through the eyes of support group leaders, patients, and caregivers will complete the agenda. Strategies for dealing with some of the more common impairments such as freezing of gait will be discussed. Our audience will include PD patients and caregivers (family, home health staff, and senior living facilities) as well as physicians and nurses. The service area encompasses an estimated 40,000 people who suffer from PD in Missouri and south/central Illinois. The chapter now reaches about 14% of these patients. State-of-the art information will be easily accessible to the underserved by mailing DVDs to libraries, churches, physician's offices, nursing homes, and senior organizations.

We are indebted to the generosity and spirit of all members of the Fraternal Order of Eagles, the charity committee led by Rhonda Lawrence and her team, Billie and Jack Tyler, and Missouri State Presidents, Joe Lambing (Aeerie) and Roxanne DeLapp (Auxiliary), for their commitment to our cause and theirs this past year. ■

Pain in Parkinson's Disease

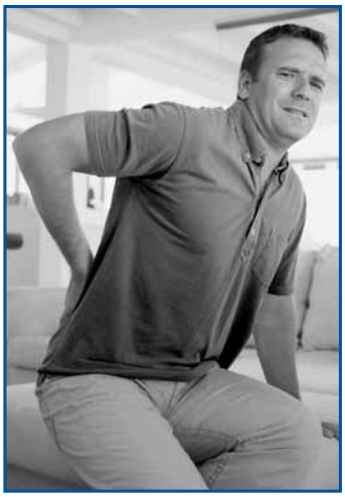
Carol Krieger, BSN, RN, MAOM, Licensed Acupuncturist, M.S. in Pain Research, Education and Policy

The motor symptoms of Parkinson's disease (PD) – the tremor, rigidity and slowness of movement or bradykinesia – are the most visible signs of the disease, but pain may be an invisible and under-treated symptom of PD that can profoundly affect a patient's quality of life. Pain may become a more distressing symptom than other symptoms of PD. James Parkinson – the physician for whom Parkinson's disease was named – noted that pain or painful sensations may be the first sign of the disease. Pain may affect nearly half of the patients with PD, with ranges from 40 – 75 percent according to published studies. The pain from PD falls into four main types: musculoskeletal pain, dystonia-related pain, radicular or neuropathic pain, and central or primary pain.

Musculoskeletal pain may be an aching, cramping pain in joints or muscles that limits joint mobility or gait, and it is related to the abnormal posture and rigidity of persons with PD. It may fluctuate with the dosing of antiparkinsonian medications such as levodopa. Physical therapy (PT), occupational therapy (OT), and exercise can decrease this pain, as well as prescription or non-prescription pain medications such as acetaminophen or non-steroidal anti-inflammatory medications such as ibuprofen. The goal of treatment for this type of pain is to restore mobility, and exercise may be necessary to prevent further problems.

Dystonia is a forceful twisting movement or muscle contraction which can lead to abnormal posture. These spasms are different from the classic writhing type of movements of dyskinesia. **Dystonia-related pain** may affect any limb, lasting just minutes or hours and can be the most painful symptoms experienced by persons with PD. Since dystonia may be related to the wearing off of Parkinson's medications, the relationship of this pain to the medication cycle needs to be evaluated. Adjustment of antiparkinsonian medications may alleviate the dystonia causing this pain. The brain stimulation treatments used to relieve dystonia may also relieve this type of pain.

Postural abnormalities may contribute to **radicular or neuropathic pain** from a compressed nerve root near the spine which may radiate along the path of the nerve. This pain may be described as burning, shooting, or stabbing, and it can be accompanied by abnormal sensations such as tingling or numbness. Treatment can include PT or OT, correction of poor posture, and medications or surgery if necessary. The primary medications indicated for this type of pain are antidepressants or anti-epileptic medications such as gabapentin.



Central pain originates in the central nervous system – the brain or spinal cord – and is a result of the Parkinson's disease process itself. Central pain is a less common type of pain in PD, affecting only 10% of patients with PD-related pain. This unusual type of pain can also occur in stroke and multiple sclerosis. It is often bizarre in its presentation, affecting the head or face, and abdomen or pelvis, and has a persistent, distressing effect, although not always severe in nature, that profoundly reduces the quality of life. As a pain resulting primarily from the Parkinson's disease process itself, anti-parkinsonian medications may reduce this pain. Since central pain is considered neuropathic pain, the anti-epileptic and antidepressant medications used to treat radicular neuropathic pain are the usual therapy. The diagnosis of central pain may be made by exclusion of other types of pain.

Akathisia may be included as a type of pain in PD, although it may be more of a sensation than pain complaint. It is defined as an inner restlessness with an intolerance to remain still and requires a constant need to change position. Similar to restless legs syndrome (RLS), it may disturb the quality of sleep. Antiparkinsonian medications are used to treat both akathisia and RLS.

It is important for patients with PD to know that both their descriptions of the pain and the relationship of pain to their medication cycles give doctors indications as to the nature of the pain. This information is necessary for optimal treatment. Pain is a subjective experience, and the response to treatment differs greatly among patients regardless of its origin.

Medications, PT, OT, and exercise are the mainstays of treatment for the two most common types of PD pain – musculoskeletal and dystonic, but they may not always provide sufficient relief. Patients sometimes turn to complementary or alternative therapies such as massage, chiropractic treatment, or acupuncture as a source of relief. The effectiveness of these therapies for pain may be difficult to evaluate by the same model used to judge the effectiveness of medications. Patients should seek the advice of their physicians and discuss their desire to try such therapies.

Despite the prevalence of pain in persons with PD, it is often overlooked by clinicians in practice, and painful symptoms may be endured without adequate treatment. The underlying cause of PD, degeneration of the neurons that produce dopamine, is not yet directly treatable. Collaboration between the patient and their physician is necessary to provide the most effective pain relief. ■

Overview of Deep Brain Stimulation for Parkinson Disease

Samer Tabbal, M.D., Associate Professor of Neurology, Director of the Deep Brain Stimulation Program, Division of Movement Disorders, Washington University School of Medicine

Deep brain stimulation (DBS) therapy consists of stimulating, using electricity, in deep areas of the brain to improve symptoms of Parkinson disease (PD) patients and other movement disorders.

The discovery that surgery may improve parkinsonian symptoms was accidental. After a stroke in the globus pallidus (a deep area in the brain) improved the tremor of a Parkinson disease (PD) patient, neurosurgeons in the 1940s attempted to burn (lesion) the same area in PD patients to improve their symptoms. Despite mixed but encouraging initial results, rigorous studies in the 1990s revealed, unfortunately, that the motor benefit of such lesions was short-lived and that making lesions on both sides of the brain often caused imbalance, difficulty speaking/swallowing, and mental adverse effects.

Electrical stimulation of the thalamus during thalamotomy was known to improve tremors in patients with Parkinson disease and essential tremor for many years. However, it was not until the early 1990s that DBS surgery became possible, thanks to the advancement in our knowledge of the brain circuits and the development of the technology to shrink the size of a stimulator from a large box on wheels to a small box that can be placed under the skin of the chest (like a pace maker). Shortly after, neurosurgeons and neurologists quit destroying deep areas of the brain and proceeded to implant stimulators in different structures of the brain.

In the last two decades, DBS has been proven to be effective in improving the cardinal symptoms of PD that include tremor at rest, muscle stiffness (rigidity), and slowness of movements (bradykinesia). Of course, most PD patients may also have, in addition, multiple other motor symptoms such as imbalance, dystonia (which refers to excessive sustained muscle contractions causing twisting around a joint), speech changes, and swallowing difficulties, as well as non-motor symptoms, such as thinking problems, mood disorders (depression, anxiety disorder and lack of motivation), sleep disorders, and autonomic symptoms (affecting the control of blood pressure, bladder, bowel movements and sweating). Although DBS therapy improves most motor symptoms, not all non-motor symptoms respond to it. In fact, some of the later symptoms may even be worsened by DBS.

The most popular areas to stimulate electrically with DBS are a small part of the thalamus, the globus pallidus, and the subthalamic nucleus. All these targets are involved in the generation of movement as well as the processing of thoughts, mood, and sensation. This is why excessive stimulation of these targets may cause adverse effects such as involuntary movements, uncomfortable tingling sensations, difficulty thinking, and mood changes. However, unlike with destroying parts of the brain where the resulting damage is often permanent, the adverse effects of DBS are reversible by adjustment of the strength of the stimulation therapy. This may be achieved by decreasing the voltage of the electricity delivered or its frequency.

Thalamic (Vim) DBS

The thalamus is a relatively large group of brain cells in the base of the brain, close to the midline. The ventral intermediate nucleus (Vim) part of the thalamus is involved in the generation of rhythmic brain cell activity causing, for instance, tremor. Thalamic Vim DBS is an effective treatment for some types of tremors resistant to drug treatment, such as essential tremor (which is an illness that consists of progressive hands, voice, and/or head tremor that occurs during an action or when holding a posture). Thalamic Vim DBS is usually performed only on the left side of the brain to improve the action tremor of the right (dominant) hand. Although Vim DBS is effective in the treatment of the tremor that occurs at rest in PD patients, its effect on PD muscle stiffness (rigidity) and slowness of movement (bradykinesia) is mild-to-moderate and short-lived. In addition, stimulating the thalamus on both sides of the brain may cause imbalance, difficulty swallowing and difficulty pronouncing words as well as memory and thinking problems.

Globus Pallidus (GPi) DBS

The internal part of the globus pallidus (GPi) is a group of brain cells that is located further away from the midline than the thalamus. GPi DBS is effective at improving tremor, muscle stiffness, imbalance, dystonia, and slowness of movements in PD. It also directly blocks the involuntary drug-induced dancing-like movements, called dyskinesia, in PD patients. This allows increasing the patient's drugs to further improve parkinsonian symptoms. Since GPi DBS improves dystonia in PD, this therapy has also been used to treat other movement disorders that have dystonia as the main manifestation.

Subthalamic Nucleus (STN) DBS

The subthalamic nucleus is a small group of cells that is almond-shaped,

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located under the thalamus. The thalamus is a relatively large group of brain cells in the base of the brain, close to the midline. In the late 1990s, STN DBS became rapidly the most commonly performed surgery for the treatment of PD complicated by motor fluctuations and dyskinesia. Indeed, it improves almost all the symptoms of PD, including tremor, muscle stiffness, slowness of movement, imbalance, drug-induced dyskinesia, and dystonia. Since STN DBS surgery remains the most commonly performed DBS surgery in PD, I will discuss it in detail, although most of the following discussion applies also for GPi DBS surgery.

What to Expect from STN DBS

STN DBS promotes the generation of movements similar to that provided by PD medication. However, unlike PD medications that provide a fluctuating motor benefit, STN DBS provides a sustained motor benefit throughout the day, because the stimulators are turned on all day. This decreases the OFF periods (the down time when the medications are not working) improving muscle stiffness, slowness of movement, and balance as well as increasing dyskinesia. The increase in dyskinesia induced by STN DBS allows decreasing the amount of medication that the PD patient needs to take, relieving the patient from drug-induced adverse effects, such as hallucinations, paranoia, confusion, and drowsiness. Since some medication may be needed in areas of the brain that STN DBS may not affect, we usually recommend that PD patients remain on, at least, a low dose of medication. At our center, PD patients were able to decrease their medication by about a half after six months of DBS therapy.

Most patients who undergo STN DBS gain weight. Although the exact reason why this is so is not known, the weight gain is most likely due to the combination of the a) overall improvement of symptoms, b) decrease in dyskinesia and muscle stiffness, and c) the decrease in the daily amount of medication. Indeed, dyskinesia and muscle stiffness burn calories like any other muscle activity, therefore, the decrease of these symptoms saves calories and promotes weight gain. Furthermore, since all anti-PD drugs are known to block appetite, taking less PD medication is likely to enhance appetite. Finally, since most PD patients lose weight when they are not doing well overall, improvement of their symptoms with any treatment (including STN DBS) tends to make them gain weight. At our center, the average weight gain after six months of DBS therapy was about 11 pounds.

The sleep pattern of patients who undergo STN DBS often improves. Again, the reason for this is not known. However, since many PD patients tend to have interrupted sleep due to the benefit of their medication wearing off at night, it could be that STN DBS improves sleep by providing a sustained medication-like effect, since the stimulators remain turned on at night.

After adjusting DBS therapy which results in marked improvement of motor fluctuations and dyskinesia, patients often switch their complaints reflecting their increase in expectations. Since dyskinesia and OFF periods quit being the main issues after STN DBS, patients shift their complaints to lesser problems, such as not being able to play basketball or walk on a tight rope. This is why it is essential to clearly establish a realistic set of goals prior to STN DBS surgery.

Finally, it is also essential for patients to realize that DBS is not the cure for PD. Indeed, DBS therapy, like medications, improves symptoms but does not reverse or stop the progression of the illness. DBS settings can gradually be increased to control motor symptoms as they progress, but there is a limit to how high the settings can be set. Nevertheless, patients will always benefit from DBS even several years after surgery, but, like medications, the benefit from DBS diminishes over time. In general, balance and thinking problems (that are not only related to dopamine deficiency) become more obvious on average by 20 to 25 years of illness. At this stage of PD, the lack of other chemicals in the brain (called neurotransmitters) becomes pronounced, including the lack of noradrenaline (that contributes to balance), serotonin (that contributes to mood and behavior), and acetylcholine (that contributes to thinking and memory). The few medications available to compensate for the deficiency of these neurotransmitters are not very effective. DBS is not effective at all in this respect.

Who is a Candidate for STN DBS

The neurologist and the neurosurgeon make a joint decision about who is a good candidate for STN DBS. Since each patient with PD has a unique combination of symptoms, it is hard to make a check list that fits all to assess PD patients for STN DBS surgery. However, some general trends apply.

The ideal candidate for STN DBS surgery would be an otherwise healthy PD patient whose best drug therapy is not providing adequate PD symptoms control, namely, someone who has bothersome OFF symptoms but whose medication cannot be increased because of drug-induced adverse effects, such as dyskinesia or mental side effects. In other words, when the motor benefit appears (also called the ON state), they have severe dyskinesia that interferes with their ability to perform their activities of daily living and affect their quality of life; when the benefit wears off (in the OFF state), they have bothersome PD symptoms, such as severe tremor, painful muscle stiffness, difficulty walking, and imbalance with falls. These patients often are in their 10th to 15th year of illness, and the motor benefit of each dose of medication usually lasts for about three hours or less. As discussed in the previous section, DBS may not be as effective beyond 20 to 25 years of illness. Therefore, the "window of op-

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portunity" when DBS is most effective at controlling PD symptoms is on average from 10-15 years to 20-25 years.

Some centers do not operate on patients over the age of 70 years presumably because such patients have difficulty tolerating the surgery that requires them to be off medications for several hours and do not respond to DBS as well as younger patients. However, several other centers (including ours) do not agree with this approach as DBS in their experience can still be life changing in patients over the age of 70 years.

During the evaluation of patients for STN DBS surgery, it is essential for the neurologist to establish that the patient had Parkinson disease rather than another form of parkinsonism. This is based on a careful evaluation of their clinical progression and neurological exam that is best performed preferably by a neurologist formally trained in movement disorders. Indeed, about 90% of patients with the combination of rest tremor, slowness of movements (bradykinesia), and muscle stiffness (rigidity) will turn out to have PD, while the remaining 10% will turn out to have other forms of Parkinson-like illnesses (generically known as atypical parkinsonism or Parkinson Plus syndrome). These illnesses are usually more aggressive than PD and do not respond to STN DBS. Actually, DBS surgery may even worsen the mental capacity and the motor function in such patients who also tend to have more post-operative complications.

Patients who would not be good candidates for STN DBS are those with significant thinking problems (dementia similar to Alzheimer disease) and serious medical illnesses, such as terminal cancer and severe heart, lung, or kidney disease. This is where the discretion and medical experience of the treating neurologist plays an important part in deciding how "significant" the dementia or the medical illness is.

How STN DBS Surgery is Performed

Each center has its own technique of inserting stimulators and programming them after surgery. In general, most centers (including ours) use a metallic frame that is fixed onto the skull of the patient using screws after applying some local anesthetic (numbing drug) on the skin and after shaving all the hair off the head (I like to call this "a complimentary haircut"). The patient is instructed not to take any PD medication after midnight prior to the surgery, which is probably the most uncomfortable part of the whole procedure. A magnetic resonance imaging (MRI) scan of the brain of the patient with the frame on is obtained to locate the STN where the stimulator will be implanted. The patient is then taken to the operating room where a hole is drilled in the skull under local anesthesia with the patient fully awake (the size of the hole drilled in the skull varies among neurosurgeons from a dime-sized burr hole to a 1/8-inch twist drill hole). A recording wire (microelectrode) is passed through the brain to listen to brain-cell firing until the typical firing pattern of the STN is identified. The recording wire is then withdrawn, and the stimulator wire (electrode) is inserted making sure that the tip lies in the STN. A hand-held stimulator is used to confirm that the stimulator wire is properly placed by checking for motor benefit (such as improvement of tremor and muscle stiffness) and adverse effects (such as bothersome muscle twitching, sustained tingling sensations, or double vision). The stimulator wire is then anchored against the skull, and the same procedure is repeated on the other side. Some centers (including ours) prefer to implant both electrodes in one surgery while other centers prefer to implant each electrode a few days apart.

Photo courtesy Washington University School of Medicine

The next step consists of inserting the stimulator battery under the skin under the collarbone and hooking it to the stimulator wire that is thread under the skin of the head and neck toward the upper chest area. This is done under general anesthesia with the patient asleep. Some centers perform this second step immediately after inserting the stimulator wire in the brain while others (including ours) prefer to do so a few days later for several reasons.

About three to four weeks after the implantation of the stimulators, the stimulators are tested and programmed for the first time in the clinic over about two to three hours. Although many patients start to feel a definite improvement within a month after initiation of DBS, it takes about four to six months to properly adjust stimulation therapy and medications. Indeed, as the DBS is increased, the medication needs to be decreased gradually.

Potential Adverse Effects of STN DBS

Just like any kind of brain surgery, STN DBS surgery carries a risk for complications. This is why the surgery is performed only as a last resort in patients where medications are not controlling disabling PD symptoms.

Since the DBS surgery involves in-

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serting a wire in the brain, bleeding inside the brain may occur causing paralysis (such as a stroke), irreversible brain damage, and even death. Centers who offer the surgery have reported different frequency of infection of the stimulators. If not attended to promptly with antibiotics or removal of the stimulators, brain infection can be fatal. The stimulator can be re-implanted a few weeks after the infection is completely resolved. Some centers have reported patients having seizures and severe depression with suicide attempt. Luckily, these are rare complications of DBS surgery when performed in the hands of experienced neurosurgeons.

A long list of DBS-induced adverse effects has been reported in the literature. Many of these adverse effects depend on the location of the tip of the electrode with respect to the "sweet spot" of the STN that provides the best motor benefit with little adverse effects. Thus the critical importance of proper targeting of the STN by experienced neurosurgeons and the use of recordings of brain-cell firing patterns during DBS surgery. Fortunately, there are four available electrical contacts (small pieces of metal) on the tip of the electrode that can be used to deliver DBS. If the contact used is too deep, it may induce dystonia, worsening of PD motor symptoms, visual symptoms (like double vision or blurring), depression, or anxiety. If the contact used is too close to the midline, it may induce visual symptoms. If the contact used is too far from the midline, it may induce muscle contractions, speech problems, and twitching. If the contact used is too shallow or if the electrode is not close enough to the tails of the STN, it will not improve PD symptoms adequately.

Deep Brain Stimulation at Washington University in St Louis

Deep Brain Stimulation for the treatment of PD has been offered at Washington University since August 1999, making our center one of the top five centers in the USA in terms of the number of procedures performed. We published in 2006 the outcome of our first 110 patients who underwent STN DBS surgery: STN DBS improved substantially the motor function of patients and allowed decreasing their medications on average to about half the amount that they were taking prior to surgery resulting in marked improvement of their dyskinesia. The surgery was completed within less than six hours which is a relatively short time compared to other centers. This minimizes considerably the time during which the patient is off medication, making the surgery more tolerable for patients over 70 years old. Our operative technique and DBS programming strategy have improved further since then, thanks to our on-going research efforts and the increasing number of patients operated (about four to six DBS surgeries per month).

The key of the success of our DBS program is the teamwork approach among our doctors, nurses, and supporting staff that is critical for optimizing each step of the process of delivering DBS therapy.

Research in Deep Brain Stimulation for Parkinson Disease

Mechanism of Action of DBS

Discovering how DBS improves PD symptoms and causes adverse effects will likely improve DBS therapy by finding the "sweet spot" to stimulate to provide maximal motor benefit and minimize adverse effects. This will also help identify other DBS targets in the brain to treat other disorders such as dystonia, tics, depression, obsessive-compulsive disorders, and seizure.

The exact mechanism of action of DBS in PD is not yet fully known although several theories have been advanced. Describing these is beyond the scope of this article. Thanks to research grants from the National Institute of Health and several other foundations, including the St. Louis Chapter of the American Parkinson Disease Association, our center has been studying the mechanism of action of DBS in PD by examining the effects of DBS on motor function, balance/gait, thinking capability, mood, and brain function using advanced imaging technique over the last decade.

Mental Adverse Effects of STN DBS

Rigorous mental testing showed that subtle thinking problems could be induced even by adequately-placed electrodes that provide excellent motor benefit with no motor adverse effects. These thinking problems are typically not severe enough for patients to notice them and often do not impair their activities of daily living. Most patients do not mind this price for the substantial motor benefit that DBS provides.

Some of the research that we are currently conducting at our center has been focused on how to avoid DBS-induced mental adverse effects by stimulating different parts of the STN.

DBS for Early Parkinson Disease?

DBS delivered over several weeks to months alters the function of the brain even after discontinuing DBS. This is loosely referred to as DBS-induced brain plasticity. Accordingly, a minority of researchers has suggested that DBS may provide a larger benefit to PD patients if performed early in the disease than after the development of motor fluctuations.

One-sided vs Two-sided DBS Surgery?

Since PD affects both sides of the body, the vast majority of PD patients require DBS for both sides of the brain. Although DBS applied on one side of the body improves motor symptoms mostly on the opposite side of the body, we and other groups of investigators have shown that STN DBS also provides motor benefit to the same side of the body, albeit to a much milder extent than to the opposite side. However, a recent study that performed DBS surgery

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Missouri Support Group Calendar

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Cape Girardeau	Cape Girardeau	The Chateau Girardeau 3120 Independence St. St. Francis Med. Ctr. 211 St. Francis Dr., SFMC Cafeteria	Feb. 1, Aug. 2 May 3, Nov. 1	3:30 PM 6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168	1st Tuesday	10:30 AM	Vicky Young Debbie Guyer	636-343-8280 314-362-3299
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Doris Heuer Mary Green	573-815-3718
Creve Coeur	St. Louis	For Caregivers Only Shaare Emeth, Library Conf. Room 11645 Ladue Rd.	2nd Monday	11:00 AM	Dee Jay Hubbard, PhD	314-362-3299
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	Linda Pevnick, MSW, LCSW, BCD Rich Hofmann	314-362-3299 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 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Julie Berthold Paula Simmons Nancy Robb	314-355-6100 314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Monday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	**Call for meeting site**	Mondays	1:30 PM	Nancy Dunaway	417-659-6694
Kirkwood	St. Louis	Kirkwood United Methodist 201 W. Adams	**Call for Meeting Dates**	7:00 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	573-964-6534
Oakland/ Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
Sedalia	Pettis	1st Christian Church (Disciples of Christ) 200 South Limit	3rd Monday	4:00 PM	Barbara Schulz	660-826-6039
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
St. Peters	St. Charles	1st Baptist Church of Harvester 4075 Hwy. 94 S.	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem.Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Griffard	573-543-2162
St. Louis	St. Louis	Pre/Post-DBS Sunrise on Clayton Senior Living 7920 Clayton Rd.	3rd Thursday	1:00 PM	Steve Balven Stan & **Donna** Wilensky	314-249-8812 314-997-5114

Illinois Support Group Calendar

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	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**
Carmi	White	Phoenix Rehab. & Nursing 615 West Webb St.	4th Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 PM	Cathy Watts	217-428-7716
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**
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Mattoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	**Bernice Baker**	**217-243-4173**
McLeansboro	**Hamilton**	**Heritage Woods - Fox Meadows 605 S. Marshall Ave., Dining Room**	**1st Wednesday**	**1:00 PM**	**Paula K. Mason**	**618-643-3868**
Mt. Vernon	Jefferson	Greentree of Mt. Vernon, 2nd Floor	4th Thursday	6:30 PM	Donna & Bill Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr.	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	**Pam Miller**	**217-698-0088**

Deep Brain Stimulation

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on one side only as a first step revealed that most patients required the second side operated within two years from the initial surgery. This is not surprising as one needs two legs to walk steadily and prevent falls.

STN vs GPi vs Thalamic DBS for Parkinson Disease?

Thalamic DBS is unlikely to become the surgery of choice for PD as STN and GPi DBS are as effective as thalamic DBS in the control of tremor, but thalamic DBS is not as effective at controlling other motor symptoms of PD.

Early studies comparing GPi DBS against STN DBS suggested that STN DBS allows a more substantial decrease in medication as compared to GPi DBS. However, a few studies argued against this. Intuitively, decreasing medications is generally beneficial since it might improve drug-induced non-motor adverse effects such as hypotension (drop in blood pressure) and drug-induced mental adverse effects (including hallucinations, paranoia, confusion, and drowsiness). Less medication means also less cost of treatment. Furthermore, STN DBS also tends to require lower DBS settings than GPi DBS. Using lower DBS settings prolongs the life of the battery of the stimulators delaying the need for replacement of the stimulator. These advantages made STN DBS the preferred therapy for PD in the 2000s, but a recent study that compares GPi DBS against STN DBS (when performed on one side of the brain) suggested that GPi DBS can provide a similar motor benefit to STN DBS therapy with less mental adverse effects. This finding, however, remains to be confirmed further. ■

Exercise Classes

Our Exercise Classes meet once a week or otherwise as noted.
Information that has changed since the last **LiNK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	Barnes Extended Care 401 Corporate Park Dr.	Wednesday & Friday	1:30 PM	Mike Scheller, OT	314-289-4202
Chesterfield	St. Louis	St. John's Mercy Rehabilitation Hospital 14561 N. Outer 40	Tuesday	1:00 PM	Deb Luetkemeyer, PT	314-881-4200
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	10:30 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	Gardenview Chesterfield 1025 Chesterfield Pointe Parkway	Thursday	2:30 PM	Faye Bienstock, PT	314-754-2180
Creve Coeur	St. Louis	Aquatic Exercise —Rainbow Village 1240 Dautel Lane	Thursday **July 14 - Sept. 15**	2:00 PM	Brenda Neumann	636-896-0999 ext. 21
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, OT	314-289-4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Ste. 117	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, PT	636-916-9650
St. Peters	St. Charles	Aquatic Exercise—St. Charles YMCA 3900 Shady Springs Ln.	Thursday **July 14 - Sept. 15**	2:00 PM	Brenda Neumann	636-896-0999 ext. 21
North St. Louis County	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534
St. Louis City	St. Louis	The Rehab. Institute of St. Louis 4455 Duncan Ave.	Thursday	Noon	Janelle Burge, PT, DPT	314-658-3858

Hull of a Race

6th Annual 5K/10K Run/Walk

"Hull of a Race" in Hull, IL

Professional Timer and Courses Certified

Saturday, August 20, 2011

7:00 a.m.-Registration

8:00 a.m.-Race

Online Registration- www.hullofarace.com

The Mark Twain Area Parkinson's Group was established in 2005 with a small group of interested people consisting of three Parkinsonians, three spouses, and the founder of the group, Lori Griffith, a physical therapist. Since that time, the group has transformed itself from a support group to one focused on "fund raising" dedicated to the idea that a cure for Parkinson's disease can be found through research. Their goal is to help fund this research, and every year they've donated the proceeds of their "Hull of a Race" to fund research conducted at the Advanced Center for Parkinson Research located at Washington University School of Medicine, one of nine such centers supported by the APDA across the nation. Their 6th annual Hull of a Race, 5K/10K competition is slated for Saturday, August 20, 2011, in Hull, IL, and to date, they have raised almost $20,000 for the cause.

Sadly, the group has lost two of its original members this past year. They crossed the finish line, but work goes on in their beloved memory and honor. Fortunately, the committee recruited some members of the West Pike High School Class of 1999 to join in their efforts. In addition, several other West Pike alumni have joined the group, and the committee has grown to nearly sixteen now. Their only goal is to plan and execute a successful 5K/10K race on the morning of the Hull picnic, which takes place on the third Saturday each August. It's a small town event but is growing each year. They've added a professional timer and lots of enthusiasm. This year, a raffle of gift certificates has been added; so tuck some money into your running attire so that you can also participate in the raffle at this year's event.

If you are a runner or walker, come to "small town USA" and experience what a small community dedicated to finding a cure for Parkinson's disease can do. Hull, IL, has "big ideas," and we support their fine work and enthusiasm! ■

Tributes & Donations

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

HONORING

The 50th Anniversary of Mr. & Mrs. Herbert Bronska
Sherry & Dick Wolff

The birth of Genevieve Juliette Daming
Karl & Debbie Guyer

The speedy recovery of Margie Frank
Lee & Harvey Shapiro

Thank you Debbie Guyer & Moury Bass for the Morning Magazine program
Kay Bruchhauser

Steve & Lynn Hurster
Mark & Nancy Kodner

The birth of granddaughter Lily Kamenetsky
Joanie & Mark Goldstein

The 70th birthday of Melvin Kraus
Colman & Toby Kraus

The 50th Anniversary of Robert & Susan Levin
Ginny & Gerry Weiss

The special birthday of Mr. Leslie Loewe
Helen & Ralph Goldsticker

Joe Marchbein
Christopher & Judith Shamel

Andre Nutis
Alice Nutis

Dr. Joel Perlmutter
Art & Jo Greenwood

The 50th Anniversary of Lawrence "Bud" & Betty Rakestraw
Jerry & Jean Sadler

The birthday of Phyllis Ross
Sheryl Browning
Kaye Cillessen
Doris Ebersole
Dee & Harry Eckert
Keith & Patty Fitzgerald
Kathy Portman
Lucille Riedel
Norm Ross
Ronald Ross

The retirement of Marty Rudloff
John & Marilyn Baker
Kevin & Marcy Baker
Mary Bardgett Family
Michael Bardgett
Andrea & Aaron Barth
Dave & Kathy Cross
Donna Dixon
Robert P. Doerr
Delores Foley
Mark & Jan Franzoi
Gerald & Carole Gassel
Danny & Janice Glenzy
Don & Joyce Groezinger
Mark & Mary Ann Haywood
Dennis & Linda Henke
Tim & Vickie Horan
Steve & Jackie Jones
John & Mary Jordan
Duke & Jenna Koeller
Gary Lee
Michael & Katherine Messmer
Tony & Mary Migliazzo
Jim & Robin Palecek
Charles & Jeanette Peterman
Richard Pflueger
Peggy Poeschel
Bruce & Virginia Saak
Richard & Antoinette Scharf
Nola & Theodore Stocker
Tina Swindle
Jerrold & Dorothy Van Deven
Sally Wahlbrink
Chris & Linda Ward
Mark & Denise Wellman
Kathleen Welz
The Zeller Family

The special birthday of Ruth Sandler
Laura & David Goldmeier
Don Hulbert
Gertrude Hulbert

The birth of Abby & Lily Schreiber
Robert & Lynda Wiens

The birthday of Martin Shrader
Judith & Steve Ellenburg
Judy Ugalde

The special anniversary of Bill & Terri Taylor
Roz Gad

The special birthday of Elaine Vanadore
Harry & Beerly Lee

In honor of David Vermillion
Lewis Ham
Amanda Hedden
Jeremy Pruden
Jason & Jenny Sorrells
Mervin & Dee Sorrells
Diane Vermillion

The recovery of Bob Wiens
Karl & Debbie Guyer

REMEMBERING

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Helen & Ralph Goldsticker
Lois Ross
Lee & Harvey Shapiro

Ruth A. Baumann
Dr. & Mrs. John S. Meyer

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Adam Levitt
Iris Levitt
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Monday, October 10, you will have the opportunity and pleasure of attending the APDA 16th Annual Focus on Fashion: a celebrity fashion show, luncheon, and silent auction held at the Sheraton Westport Chalet. Our theme this year is ***Guys and Dolls*** and is based on Nancy Green's donation of over 50 collectible dolls which will be showcased at the silent auction. Kent Ehrhardt, KMOV Channel 4 Meteorologist, and Victoria Babu, KTRS 550am News Director and news anchor of the morning drive, will be returning by popular demand to be Masters of Ceremonies. We are also thrilled to announce that Steve and Lynn Hurster will serve as our Honorary Chair Couple this year. In addition to Kent and Victoria, additional TV, radio, and film personalities, and favorite St. Louisans will be on stage serving as celebrity models. This year's show will feature fashions for women, men, and children from Paper Dolls, Cha, Savvi Formalwear, Jilly Bean, Alpine Shop, Petunia, PURE by Jen, Vie, Chocolate Soup, Ann Taylor, and Jos. A. Bank. You will be entertained by attractive models, served a scrumptious lunch, and enjoy shopping at kiosks and the silent auction!

Look for your invitation to arrive in the mail by Labor Day. If you've never received an invitation to this charitable event, please call the center and request one! Our Auction Basket Committee promises a return of some of the very popular auction items, along with our annual St. Louis Buffet (gift certificates to favorite restaurants) and kiosks featuring items for sale. We are bringing the boutiques to you, the shopper. We look forward to a fun and memorable day celebrating our progress toward finding a cure!

For more information, to become a sponsor of this event, to donate an auction item or gift certificate, or to request an invitation, please call 314-362-3299. ■

Family Tributes

At the 2010 Fall Fashion Show, we introduced the Family Tribute Program. This program honors the life of a person and their family living with this disease every day, who continue to do so with grace and style. Family members and friends have an opportunity to make contributions in honor of a person with Parkinson's disease, and a certificate is presented at the luncheon to this recipient and/or their family representative. We are proud to report that this beautiful Family Tribute tradition will continue at this year's fashion show event on October 10. We hope that you and your family will consider joining us in commemorating milestones and celebrations as we congratulate families participating in this special program by giving recognition to them at the 2011 Fashion Show.

In order to qualify for a Family Tribute, a minimum of $1,000 must be contributed collectively in honor of a person/family. These Family Tributes will be acknowledged in the newsletter, and a certificate will be presented and/or mailed to the recipient. Feel free to contact Debbie Guyer at 314-362-3299 to discuss Family Tributes in greater detail. We look forward to recognizing additional families at the 2011 Fashion Show in October. ■

2011 Golf Tournament Hits A Hole-In-One!

We were very privileged to have **John Mozeliak, GM of the St. Louis Cardinals**, serve as our Honorary Chairperson again this year. No matter how you slice it, our 13th annual Nat Dubman Memorial Golf Classic was one of the best tournaments ever, and we managed to dodge the rain and the cicadas on May 16 at beautiful Lake Forest Country Club.

Our success was due in large part to our loyal sponsors, many who have supported us through the years: **MASTERS** level sponsor - **Benton Homebuilders Community Partnership**; **MAJOR** level sponsor - **Carol House Furniture**; **CHAMPION** level sponsors - **St. Louis Cardinals** and **Flexsteel**; **COCKTAIL RECEPTION** and **BEVERAGE CARTS** sponsor - **The Moneta Group Charitable Foundation; DRIVING RANGE** sponsors - **Lane Home Furnishings, Largo** and **Schnadig International**; **PRACTICE GREEN** sponsor - **Pulaski Furniture**; and **HOLE** sponsors - **American Drew/Lea & Hammary, A.R.T. Furniture, Don Carlson, The Commerce Trust Company, Continuum, Craftmaster Furniture, Larry & Sonya Davis, The Delmar Gardens Family, Glideaway Sleep Products, Grey Eagle Distributors, Guarantee Electrical, Keith & Cindi Guller, Huntleigh Bus Sales, Medical West Healthcare Center, PNC, Serta Mattress, Shillington Box Company, Universal Furniture,** and **Weintraub Advertising**.

CHARITABLE CONTRIBUTIONS arrived in generous proportions from the following donors: **Enterprise Bank & Trust, Pat Farrell, Keith Guetschow, Marc Hulsey, Ron & Sharyn Kessler, Lane Furniture, Michael Lefton, Alan Lemley, David Link, Robert May, Stephanie McFadden, Frank Miskit, The Moneta Group Charitable Foundation, Mel Moskowitz, The Rachlin Group, Les Reiter, Dave Sadler, Marty Satz, Mark Schupp, Rick Short, Freddie Steinbach, Sandy Steppig, Jack Strosnider, Addie Tompkins, Dan Touchon, Mark White, Mark Wilson, Brad Wood,** and **Marty Zygmund**.

Larry Hartstein

AUCTION ITEMS were donated by **Autohaus (Rusty Yost), Bimmer's R Us (Steve Yost), Bob Costas, Garden Villas South (Jeannie Lorne), Golf Discount of St. Louis-Manchester, Art Harper of Garland Wines, John Mozeliak, PRP Wine International, Tom Seeger from Seeger Toyota, St. Louis Cardinals,** and **Wines for Humanity**.

John Mozeliak

And caps off to these special **VENDORS** who willingly came out of the rough and sank the putt through these in-kind donations: **Alphagraphics (Bob Sanderson)** for the wonderful invitations, flyers, and program booklets; **Paramount Apparel International (Alex Levinson)** for their hoodies (which were needed at the start on this cold day); **Natixis Global Associates** for the sleeves of golf balls for our golfers; **Golfsmith** for their $10 gift cards for each golfer; **Crazy Bowls & Wraps** for their classic rice bowl with teriyaki chicken, salsa and chips; **Flemings Prime Steakhouse & Wine Bar of Frontenac** for their delicious seared tuna and slaw; **Donatelli's Bistro of Lake St. Louis** for their tasty chicken spedini; **Viviano's Festa Italiano of Chesterfield** for their deli sandwiches, cheese, and olives; **The Ritz Carlton of St. Louis** for their yummy gourmet cookies; **Lodging Hospitality Management at the Sheraton Westport (Frank Ikemeier)** for the bushel of apples, oranges, and bananas consumed on the course; **Garden Villas Retirement Communities (Jeannie Lorne, Wendy Hampton, and Mary Ann Meyer)** for their Cooler of Fun raffle and shots on the course; and our two hole-in-one sponsors, **Autohaus and MINI of St. Louis** for the much coveted brand new MINI Cooper Countryman, and **David Kodner Personal Jeweler** for the 3-carat diamond

valued at $ 25,000. Photos were courtesy of our APDA photographer, **Cathy Hartman**, who captured all those action shots and is responsible for the pictures both on our web site and in this article.

Brook Dubman, Shari & Bill Reller, Bud Rakestraw, David Elhoffer

None of this could have been accomplished without the hard working 2011 Golf Committee under the direction of **Chairman Brook Dubman: Elaine Dreher, Debbie Guyer, Matt LaMartina, Shari Reller, Christine Sadler, Bob Sanderson, Carrie Taylor Terri Taylor, Stan Wilensky,** and **Tracy Wright**. A big thank you for our tireless volunteers from **Elsevier** who spent the day with us at registration and on the course: **Gina Bargmann, Tom Betzen, Dave Dipazo, Lara Gniadek, Maureen Niebruegge**, and **Dawn Vohsen**. Amazing were our auction room volunteers and food servers: **Ann Cook, Susan Westermeyer,** and **Lynda Wiens**. Many thanks to Debbie's unfailing assistant at the registration table and during check-out, **Elaine Dreher**, and the games "barker," Executive Board Member **Bob Goldsticker**. **Nellie Dankmyer** and **Elinor Pullman** helped stuff goodie bags and served food on the course. **Whitney Jones** and **Erin Waldron**, and **Terri and Carrie Taylor** also helped with welcoming all the golfers and distributing goodie bags, before getting seated in the beverage carts to provide beverages and snacks on the course throughout the day.

Thank you to the 104 golfers who had a terrific day on the greens, bidding on many wonderful auction gifts, feasting on mouth-watering hors d'oeuvres, and enjoying the Question & Answer session with John Mozeliak before he headed off to the ballpark for the game. We marveled at the ease at which **Matt LaMartina**, auctioneer-extraordinaire, secured great bids for our one-of-a kind live auction items including an autographed Matt Holliday game bat, party room for 45 including food and beverages at the ballpark, Phil Mickelson Masters flag, Stan Musial autographed jersey and baseball, Lance Berkman and Taylor Swift matted and signed photos, and Bono autographed guitar. We've already reserved Lake Forest for next year's golf classic. If you would like to volunteer to join our golf committee or wish to receive an invitation for next year's golf tournament, please call the center at **314-362-3299**. ■

Matt LaMartina

Dave & Christine Sadler, Katie & Jamie Harrell

SAVE THE DATE!

Monday, May 21, 2012
10:00 AM shotgun start

Craig Goldford, Larry Hartstein, Bill Taylor, Bob Cohen

Washington University School of Medicine
American Parkinson Disease Association
Campus Box 8111
660 S. Euclid Ave.
St. Louis MO 63110
Address Service Requested

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Save These Dates!

Mon., Oct. 10 **Focus on Fashion "Guys & Dolls"**
Sheraton Westport Chalet in Creve Coeur
RSVP required; invitation to follow.
Volunteers wanting to serve on the fashion show or auction committee are encouraged to contact the center.

Sat., Nov. 12 **Parkinson Education Program (PEP)** ***What's New, What's Now, What's Next***
Dr. J. William Langston, Scientific Director, CEO and Founder of the Parkinson's Institute in Sunnyvale, CA, and Susan C. Imke, RN, MS, Family and Gerontological Nurse Practitioner, will join us at the St. Charles Convention Center for a very special program. Dr. Langston's current research interests include the study of mechanisms of neuronal degeneration, the etiology of Parkinson's disease, and the development of new strategies to slow or halt disease progression. Susan Imke will speak on the topic of Family Caregiving: Choices and Challenges, including practical management of anxiety, depression, delirium, and dementia. Sponsored by TEVA Pharmaceuticals

New Satellite Resource Center Hours

Our search for additional volunteers for our satellite resource center has resulted in the addition of four new volunteers and new hours of operation. Please note that our satellite center at 1415 Elbridge Payne Dr., Suite 168, in Chesterfield will now be open on Mondays, Tuesdays, and Thursdays from 11:00 a.m. – 2:00 p.m. We ask that you call ahead to make certain that volunteers Marilyn Warren, Jeanne Hogenkamp, Art Spellmeyer, Brenda Wilsey, Ann Cook, or Lynda Wiens are available to meet with you. Remember that special arrangements may be made to meet you there at other times, when possible.