

APRIL 2013

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**2013 HAPS
ANNUAL EDUCATIONAL
SYMPOSIUM
APRIL 27TH
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Parkinson's Awareness Month

In 1817, Dr. James Parkinson's, a British physician, first described the disease in a detailed medical publication called, "An Essay on the Shaking Palsy." The essay was based on six cases he observed in his medical practice and on walks through his neighborhood. Sixty years later, French neurologist Jean Martin Charcot was the first to truly recognize the importance of Dr. Parkinson's work and named the disease after him.

Today, nearly 200 years after Parkinson's disease was first identified, there are over one million Americans and seven to ten million people worldwide living with the disease. Despite the progress that has been made in understanding and treating Parkinson's, there is still much that remains a mystery and so much more that needs to be done to find a cure.

Together, with millions of others around the world, we recognize April as Parkinson's Awareness Month. This month we pay particular attention to working together as a community to educate ourselves and others about Parkinson's and the challenges faced by those living with the disease. There is no effort too small and everyone can find a way to participate. Join HAPS this April as we work together to make a difference in the fight against Parkinson's. Here are some of the ways you can get involved:

- *Wear a Parkinson's disease or HAPS t-shirt*
- *Distribute HAPS brochures to your neurologist and tell your doctor how HAPS has helped you and how it can help others with Parkinson's*
- *"Like" HAPS on Facebook or follow HAPS on Twitter*
- *Attend the HAPS Annual Educational Symposium on April 27th, the upcoming Summer Lecture Series during the summer months or the 3rd World Parkinson Congress in Montréal October 1-4, 2013*
- *Start a "Dress Casual Day" at work to raise money for the Parkinson's cause*
- *Share your story with HAPS. Send us a paragraph or two about your experience with Parkinson's and the role HAPS plays in your life along with your picture and each week HAPS will feature a different client story on Facebook. You may send stories and pictures to HAPS at 2700 SW Freeway, Suite 296 Houston, TX 77098 or via email at nicholls@hapsonline.org*
- *Visit the HAPS website and click the YouTube icon to watch the new HAPS videos; share the link with family and friends*
- *Attend a HAPS exercise or support group and meet others living with the diagnosis*
- *Sign the Global Parkinson's Pledge at www.parkinsonspledge.org and join the global movement to highlight the urgency for better care for people with Parkinson's*

Get started this April and help make every month Parkinson's Awareness Month!

Understanding the Progression of Parkinson's

By Ronald F. Pfeiffer, MD

When a diagnosis of Parkinson's disease (PD) is made, one of the first things that my patients and their loved ones ask is, "What is going to happen? How is this disease going to progress?" As doctors, we do our best to help people with PD and families to understand the disease and the changes that may occur in the future.

First, I tell my patients, PD progresses slowly. There is time to prepare for changes because they develop gradually rather than suddenly.

Second, I believe it is important to let people with PD know that the manner in which the disease develops and progresses varies greatly from person to person. Some people may have trouble with a particular symptom, such as tremor, that another person never will experience at all. This variability applies also to the place at which Parkinson's disease progresses. Some people experience only mild symptoms for many years, and respond well to medications. For others, the disease may progress more quickly.

Currently it may not be possible to predict how someone's PD will progress or to provide treatments to slow its course, but research shows that the average lifespan of people with PD is only slightly less than people without it. There are many strategies that can help people with PD to manage the disease most effectively over the years and to feel their best.

MOVEMENT SYMPTOMS AND COMPLICATIONS

It is likely that what brings someone to the doctor for a suspected PD diagnosis is one of the movement symptoms, such as tremor, slowness or rigidity. Most people initially will experience one of these symptoms on one side of the body and want to know: will those symptoms extend to the opposite side of the body?

For some people with PD, their symptoms remain confined to one side of the body for a considerable time, but in most people, movement symptoms will progress to the other side of the body, although they are likely to be less severe on the more recently affected side.

Most people with PD eventually will experience some level of movement fluctuations, which are caused by the medications used to treat PD. Studies show that 15 years after PD diagnosis, more than 90 percent of people will be aware of a gradual shortening of the duration of benefit from a dose of levodopa, which is termed "wearing-off" and more than 90 percent of people will be experiencing dyskinesia — that is, involuntary twisting and writhing movements.

These two types of fluctuations occur when people with PD have been treated for some time with levodopa, which is the gold-standard therapy for movement symptoms. "Wearing-off" usually begins, on average, around six years after levodopa was first prescribed, although it may appear much earlier in some persons. For most people, though not all, it is not particularly severe or disabling and wearing-off time occupies less than a quarter of the waking day. The same is true of dyskinesia. More than a decade after starting levodopa therapy, as many as 50 percent of people with PD report that the dyskinesia they are experiencing is not disabling; only 12 percent describe it as severe.

COMMON NONMOTOR SYMPTOMS

In recent years, recognition has grown that the most troubling issues for many people living with PD are nonmotor symptoms, which are features of PD that have little or nothing to do with movement. It is important for people with PD to be aware of these nonmotor symptoms so that they can recognize them and discuss them with their doctor. Effective treatment is often available.

Falls: Falls are an important concern; more than 80 percent of people with PD experience falls within 15 years of diagnosis. Although medications generally do not eliminate the balance impairment that often leads to falls, and falls cannot be completely prevented, measures that will reduce significantly the risk of falling can be undertaken. Physical and occupational therapists can help reduce the risk through such strategies as exercise programs or simple changes in the home.

Orthostatic hypotension (low blood pressure): Some 35 percent of people with PD, within 15 years of diagnosis, will experience orthostatic hypotension (OH), which is a drop in blood pressure that occurs when a person stands up. For most people, this will mean feeling dizzy and lightheaded when getting up from a chair or out of bed. If OH is severe, it can lead to

falls and even to a loss of consciousness. There are a variety of causes for this condition — from PD itself, to the medications used to treat it, to dehydration — and for each of these there are strategies (including medications) available to treat it.

Bladder and bowel problems: Issues with gastrointestinal and urinary functions are relatively common, with about 40 percent of people with PD experiencing urinary difficulties within 15 years of diagnosis. For many people, this means frequency; for a smaller percentage, it may mean incontinence. Constipation is also common; about 40 percent of people with PD use laxatives on a daily basis by 20 years after diagnosis.

Cognitive changes: The prospect of cognitive change — impairment of memory and other thought processes — can be of greater concern than anything else for someone who is newly diagnosed with PD. Such changes do occur, but they happen slowly and do not necessarily become severe. Among people who have had PD for 15 years, significant cognitive difficulty has developed in just under 50 percent, but about 35 percent have only mild difficulty and 15 percent have experienced no significant changes. The changes in thinking and memory that occur with PD are not identical to those of Alzheimer's disease and often are less severe or disabling.

Hallucinations: The medicines used to treat PD can sometimes cause hallucinations. More rarely, hallucinations appear as part of PD itself. Although about 50 percent of people with PD will experience them within 15 years, medication adjustments can often reduce and sometimes eliminate hallucinations completely.

LIVING WELL WITH PD

How can a person ensure that his or her PD is managed most effectively? Here are some strategies:

See a specialist: An important step is to see that the person receives care from a neurologist who specializes in PD — ideally a movement disorders specialist. People with PD who live too far from a specialist should consider seeing a knowledgeable general neurologist on a regular basis, and then traveling a longer distance to see a specialist a few times a year.

Build a health care team: Beyond simply seeing their neurologist, people with PD should take advantage of the other health care professionals who can help make their lives easier. Physical therapists can help a person improve strength, balance and flexibility; occupational therapists can suggest ways to make the home environment more accessible and reduce the risk of falls; speech therapists can help a person feel more at ease in social situations.

Take medications on time: People with PD should be sure to take all of the medicines that the doctor prescribes, and to take them on time. This can be difficult to manage if a person is taking medicine every few hours, but PD medications will be most effective at controlling symptoms when they are taken at the times prescribed. If problems with the medications are encountered, discuss this with the treating neurologist so that medication adjustments can be made. For some individuals, deep brain stimulation surgery may be an appropriate treatment approach.

Read and learn about PD: What you do not know, you fear, and what you fear can make life with PD much more difficult to manage. People with PD should be sure to educate themselves by reading, learning, attending support groups — and seeking information from groups like PDF.

Exercise: Exercise can help a person with PD maintain and even improve mobility. Recent studies have shown that people who exercise regularly are more successful in managing their PD. Although all types of exercise (aerobic, resistance, yoga — even boxing!) are helpful, recent studies have suggested that Tai Chi and dance therapy might be particularly beneficial in addressing the balance impairment and other movement difficulties associated with PD. Even more exciting, there is some developing evidence that exercise may actually slow PD progression, although this has not been definitively proven.

Expect the best, plan for the worst: Everyone can benefit from planning ahead for health care and retirement, but for someone with PD, such planning is even more important. For example, many people continue to work after PD has been diagnosed. Although the decision when to tell an employer about PD, or when to stop working, is entirely individual, it may be beneficial to think about this earlier rather than later, in order to arrange for accommodations and to plan a solid financial future.

People with PD should consider discussing issues like driving and long-term care with loved ones before they become immediate issues. Although a diagnosis of PD doesn't by itself make driving dangerous, PD progression and the medications used to treat PD can result in problems such as slowed reaction time and excessive drowsiness that make driving unsafe.

Continued on page 6

Tango for Parkinson's

Research on the benefits of Tango for people with Parkinson's is not new, but the topic has generated significant attention since Gammon Earhart, PT, Ph.D, started studying differences in movement patterns between people with Parkinson's disease and those without the disease. She wanted to explore the phenomenon of "freezing" or the sudden, temporary inability to move, common for some people with Parkinson's as they turn around. Hearing about a study involving older adults at high risk for falls and the improved balance they experienced through learning to dance Argentine Tango prompted Dr. Earhart's research path. Could learning to dance Tango also improve balance for those living with Parkinson's disease?

For Dr. Earhart, it made sense – Tango uses many of the movements such as balance, turning, starting, stopping and walking backwards that can be a struggle for people with Parkinson's. Learning to dance the Tango could provide an opportunity to learn new ways of moving and apply those strategies to real life, so she formally began studying Tango and how it affected people with Parkinson's.

In 2010 and 2011, Dr. Earhart received funding through the Parkinson's Disease Foundation's International Research Grants Program. Her study included 52 participants with Parkinson's disease who were experiencing problems with balance and movement. Under the supervision of Dr. Earhart and her colleagues, half of the participants were assigned to take Tango lessons for one year and the other half simply maintained their normal activities. The results showed that many of the participants involved in the Tango activity showed improvement in their Parkinson's symptoms while those not involved in Tango experienced either no change or worsened Parkinson's symptoms.

Dr. Earhart and her colleagues also found that the group of participants who had learned Tango showed increased participation in leisure, social and household activities not found in the group who didn't participate in learning Tango.

Dr. Earhart and her colleagues published these findings in two medical journals and now she is starting her next research topic, investigating the role

exercise plays in slowing or stopping the changes that take place in the brain with Parkinson's.

Based on Dr. Earhart's research on Tango, HAPS initiated a ten week pilot project in the fall of 2008. The results were amazing and participants demanded more! In February 2009, HAPS began a weekly Tango class that has grown to include an additional weekly beginner class offered in partnership with the Parkinson Foundation of Harris County, and dance parties known as Milongas which are held several times a year. Over the past four years, HAPS Tango dancers have found that participating in weekly Tango classes have improved their balance and movement. Additionally, participants reported having greater connections with others and decreased isolation.

The initial success of the Tango class prompted HAPS to explore other types of dance as alternative options to traditional exercise. In the spring of 2009, HAPS began a weekly *Dance for Parkinson's* class offered in partnership with the Houston Ballet, modeled after the groundbreaking program started by Mark Morris Dance Company and Brooklyn Parkinson Group in New York. This group is held at the Houston Ballet's Center for Dance and features live piano accompaniment and various types of dance styles in seated and standing activities.

HAPS is proud to offer innovative programming to the Parkinson's community and we hope that you will join us on the dance floor. For more information about the Tango classes or *Dance for Parkinson's*, contact the HAPS office at 713-626-7114.

Reference: Parkinson's Disease Foundation. 2013. Teaching tango for Parkinson's. *News and Review*, Winter 2013, 3.



Join Parkinson's Disease Foundation's Special PD Expert Briefing in Recognition of April's Parkinson's Awareness Month

Medical Therapies: What's in the Parkinson's Pipeline?

Tuesday, April 16 12:00—1:00pm CST

Kapil D. Sethi, M.D., F.R.C.P., Georgia Health Sciences System, Augusta, GA

Available online or by phone. Pre-registration is highly recommended. 1-800-457-6676 or pdf.org/parkinsononline

This series has been made possible by educational grants from AbbVie Inc., Teva Neuroscience and UCB Inc.



HELP HAPS REACH 1,000 "LIKES" on FACEBOOK

We need your help to spread the word about HAPS services and raise awareness of Parkinson's disease. Please tell your friends to tell their friends to "Like" us on Facebook. Help us reach 1,000 "Likes" by October!

NEW CYPRESS AREA EXERCISE GROUP

Beginning May 7th

HAPS will offer a new exercise group in the Cypress area.

Tuesdays
12:00—1:00 pm

**HealthSouth Rehabilitation
Hospital of Cypress**

**13031 Wortham Center Drive
Houston, TX 77065**

Participation is limited—call Alfonso Hernandez for more information at 713-520-8670.

PROGRESS FOR PARKINSON'S



Miss Fairview 2013 Whitney Wylie is back in pursuit of the Miss Texas crown. She held a frozen yogurt fundraiser for HAPS on Monday, March 18th as she continues to promote her platform, *Progress for Parkinson's*. This initiative, inspired by her grandmother who had Parkinson's, aims to raise awareness of the disease and advocates for the importance of finding a cure. Thanks Whitney for your ongoing support and good luck in the competition!

DBS DISCUSSION GROUP

Learn more about Deep Brain Stimulation as a treatment option for Parkinson's. This session will explore the surgical procedure; how DBS works; who is a good candidate; which Parkinson's symptoms benefit most and for how long; what to expect before and after surgery; and what defines DBS success.

PRESENTERS
Dr. Richard Simpson
Dr. Eugene Lai

Wednesday, May 8, 2013
6:00-8:00 pm
2700 SW Freeway
Houston, TX 77098

Call 713-626-7114 or email cris@hapsonline.org to register

Presented in partnership with Medtronic

Long-term care needs also become important as PD progresses. Advance planning that takes into account both family support and finances is important to avoid situations in which care decisions must be made on an emergency basis and choices might be limited.

Build connections, expect resilience: In other disease areas, such as cancer, research indicates that one factor in determining why some people fare better than others is “resilience.” Boiled down, resilience comes from the supportive relationships and meaning that we create in our lives. For a person with PD, it can mean finding an enjoyable social group — whether PD-related or not — spending time with family, having a beloved pet, or taking a walk each day. It means striking a healthy balance between the management of PD and maintenance of the important connections and activities that ensure that life isn’t just about the disease.

CONCLUSION

PD progression is a complex subject that involves the inter-relationship of disease pathology, symptoms and treatments. In looking at disease progression, it is natural to primarily focus attention on the process of improving treatments, but it also is important to focus on “life progression” as a whole — how people with PD can take an active role in managing their PD in the context of living happy and successful lives.

Dr. Pfeiffer is Professor and Vice Chair, Department of Neurology and Director, Division of Neurodegenerative Diseases at the University of Tennessee Health Science Center in Memphis, TN.

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The Importance of Exercise in Parkinson's Disease

By Stanley Fisher, MD

The importance of exercise for healthy people as well as people with chronic illnesses cannot be overemphasized for multiple reasons. It produces essential well-being, maintains physical endurance and strength, helps with fall prevention, improves aerobic activities, safeguards against vascular disease and obesity as well as other innumerable benefits.



In patients with Parkinson’s disease, the importance of exercise goes way beyond those accepted parameters. One of the cardinal features of Parkinson’s disease is poverty of spontaneous movements. Even very early in the disease process, patients who develop Parkinson’s have decreased spontaneous movements, which over a long period of time create, through inactivity, dramatic changes in multiple structures including joints, ligaments, tendons and muscles. It has been documented in many studies that one of the first presenting complaints of patients with Parkinson’s disease when seen in the movement disorder clinic, is shoulder pain on the side initially affected by the disease. It is very possible that this phenomenon is due to a decrease in spontaneous movements, and it is my experience that it is often relieved by treatment and aggressive exercise. Therefore, daily stretching and range of motion exercise can prevent development of pain and stiffness, and slows down the arthritic changes that otherwise would develop in patients with advancing Parkinsonism. Another mechanical advantage of exercise comes from maintaining the ability to walk safely in patients who developed balance problems and freezing of gait. Lack of effective treatment led to the research on the rehabilitative techniques that are most helpful in the treatment and arrest of symptoms related to freezing of gait. One of the most effective therapies discovered is walking at a rate setup by a machine, like treadmill exercise.

In addition to those simple benefits, from the very early history of Parkinson’s disease researchers noticed that intense exercise creates not only a sense of well-being, but improves Parkinsonian symptoms immediately after completion as measured by the improvement in UPDRS and “time up and go” testing. The aggressive exercise routine in the laboratory animals studied showed protective effect against the toxin-induced Parkinsonism on multiple occasions. The Cleveland Clinic research on tandem cycling, where a Parkinson’s patient is forced to cycle at the rate setup by the stronger leader, showed lasting improvement in symptoms similar to low dose of dopaminergic agonist. There has been consistent evidence in animal research that shows an increase in specific chemicals in the brain called neurotrophic factors after aggressive exercise that may potentially result in some protection against the disease and contribute to slowing down the disease progression. This data, however, requires confirmation.

CONTRIBUTIONS

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While we make every effort to be accurate and thorough, it is possible to accidentally omit or misspell a name. Please contact the HAPS office with corrections.

Exercise continued from previous page

What does not require any further confirmation is the overwhelming affect of exercise in patients with Parkinson's disease on every level from maintenance of basic activities of daily living, prevention of falls and improvement in range of motion to aerobic health and feeling of well-being.

In addition, there has been overwhelming evidence that persistent physical exercise also slows down the cognitive decline in patients with neurodegenerative dementias. Since a certain proportion of patients with Parkinson's disease are at risk of developing dementia that is an added bonus of regular exercise.

It is more important to exercise than to decide what to do. To begin you have to see your physician and be evaluated on the safety of exercise for you. Most of the patients have to start with physical therapy in order to learn safe and appropriate exercise before they venture on their own. High level patients may go to the fitness centers and work with personal trainers. It is less important what you decide to do: be it pure range of motion and stretching exercise like yoga and Pilates combined with mild aerobics, or doing something as complex as ballroom dancing—the benefit is obvious. For the patients with advanced disease who are prevented from doing strenuous exercise by their symptoms or by freezing of gait, there are specialized centers that can utilize robotically assisted technology to help them to overcome those symptoms and maintain the function at the current level.

Dr. Stanley Fisher, MD is Co-Director, Movement Disorders and Neuro-rehabilitation Center and member of the HAPS Medical Advisory Board. His primary interests include medical and surgical treatment of Parkinson's disease, tremor, dystonias, and Tourette's syndrome, as well as Neurological Rehabilitation utilizing intrathecal baclofen and botulinum toxin. An internationally recognized expert in the field of Neuromodulation, Dr. Fisher collaborates extensively with the researchers and engineers at the Center for Neuromotor and Biomechanics Research and is a member of the faculty of the Department of Health and Human Performance at the University of Houston.

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