

OCTOBER 2012

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**3rd Annual Parkinson's Caregiver Conference: Preparing for Change**

**Saturday 12.8.12**

Look for more information in the November newsletter.

This publication is not intended to provide diagnosis or treatment. Always seek the advice of your physician or pharmacist with questions regarding medical conditions or drug interactions.

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Neuroscience



## THINK GLOBALLY...

There are an estimated 22,000 individuals in the Houston area with Parkinson's disease, over a million people living with the disease in the United States and as many as seven to ten million people affected worldwide. These numbers don't include the family members and friends who are also involved in the care and lives of those diagnosed with PD— or the scientists, physicians, allied health professionals or support organizations who work daily to further efforts in conquering, or at the very least, helping people live with this devastating disease.

Parkinson's is not just something that happens in our local living rooms, waiting rooms or support groups—Parkinson's is a worldwide issue. There are so many important initiatives taking place all over the world in the field of Parkinson's that we have much to be excited about and a lot to learn. Advances in science and innovative ideas in treatment or management approaches benefit the entire Parkinson's community no matter where they were developed.

The month of October officially gives the Parkinson's community 12 months to prepare for the 3<sup>rd</sup> World Parkinson Congress (WPC) which is scheduled for October 1-4, 2013 in Montréal, Canada. Sponsored by the World Parkinson Coalition, the 3<sup>rd</sup> WPC, is poised to be just as successful as the first two conferences by providing an international forum for the latest scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. The WPC brings together doctors, scientists, rehabilitation professionals, caregivers and people with Parkinson's disease. All convene with the goal of creating a worldwide dialogue that will help expedite the discovery of a cure and that focus on best treatment practices for Parkinson's through an extensive program of plenary sessions, symposia, and workshops with presentations and discussions.

As one of the 146 Organizational Partners from 43 countries, HAPS is dedicated to being part of building a unified and effective Parkinson's community. You too can be a part of this global initiative to gain greater understanding of Parkinson's.

Join HAPS as we participate in events leading up to the WPC. And if you can't travel with us to Montréal next October you can still take part by telling your story through the *WPC 2013 Video Competition*. You can help elevate awareness of Parkinson's disease globally by sending your message via YouTube. You are invited to make a video about your experience with PD and to share your journey with the larger community on the **Road to a Cure**. The WPC works to advance science, promote community, and inspire hope and sees the use of video as an effective way to help further those goals. The individual paths each of us takes can come together at the WPC as we all learn from each other. The video submission site opens November 5, 2012. Videos must not exceed the three minute and thirty seconds limit and must be submitted before May 8, 2013. Go to the World Parkinson Congress website, [www.worldparkinsoncongress.org](http://www.worldparkinsoncongress.org), for more information about rules and contest prizes.

HAPS will keep you up-to-date in the coming months as more details about this exciting event unfold.

By Kathleen Crist, LMSW

**"To accelerate the quest for a cure, it stands to reason that all the stakeholders should come together as one to discuss, collaborate, debate, plan and influence the future of Parkinson's and the lives of the people it affects" - WPC 2010 delegate**

# CHANGING the face of PARKINSON'S

It's that time again to put on your dancing shoes and snazziest outdoor cocktail attire for HAPS' 2012 Annual Awards Event, *Changing the Face of Parkinson's*, on Sunday, November 4<sup>th</sup> at The Bayou Club. This year's event is hosted by co-chair couples Martha and Terry Satterwhite and Biba and Jon Parker. Provide your palate with a pleasurable poolside dinner, with the musical stylistics of the band *Commercial Art* providing fabulous entertainment. Join us as Mistress of Ceremonies Courtney Zavala honors the Ray C. Fish Foundation and Doug Benzuly with awards for the exceptional contributions they have made to those living with Parkinson's. Don't forget to pick up some raffle tickets throughout the night and increase your chance to win exciting travel, jewelry and entertainment prizes. Tables and individual tickets are available with prices listed below. For more information or to purchase tickets, call Kelly Nicholls at 713-313-1621. Please join us for this fun evening to help generate funds that support HAPS services and pay tribute to this year's honorees.

HOUSTON AREA PARKINSON SOCIETY  
Annual Awards Event \* 2012  
CHANGING  
The face of  
PARKINSON'S

UNDERWRITING OPPORTUNITIES and TICKETS

<i>Tables</i>	● SILVER at \$2,500 Reserved table for 8	<i>Individuals</i>
● PLATINUM at \$10,000 Reserved table for 10	● BRONZE at \$1,500 Reserved table for 5	● TICKETS \$150 per person
● GOLD at \$5,000 Reserved table for 10	● COPPER at \$500 Reserved table for 2	● YOUNG PROFESSIONAL TICKETS \$75 per person

## HONOREES:

The Roy H. Cullen Quality of Life Award is presented to a person or an entity in recognition of having helped improve the quality of life for people living with Parkinson's disease through leadership, wisdom and generosity. The **2012 Roy H. Cullen Quality of Life Award recipient is the Ray C. Fish Foundation** in recognition of its commitment to the Parkinson's community through ongoing generous support of HAPS programs for 22 years.

The Lillie Cullen Quality of Life Award is presented in memory of Lillie Cullen, daughter of Roy H. Cullen, in recognition of an individual who lives life or who helps others live life with purpose, dignity and courage amid the challenges that come with being diagnosed with Parkinson's disease. The **2012 Lillie Cullen Award Quality of Life Award recipient is Doug Benzuly** who is being honored for his incredible vision, drive and ambitious efforts in creating the annual event, *Playing for Parkinson's*, to increase awareness of the disease and raise funding for the cause.

## Join Us!

You are invited to the first-ever **Pumps and Purses for Parkinson's** event sponsored by Elaine Turner.

Meet your local KPRC Channel 2 Anchor and HAPS Board Member Courtney Zavala as she hosts this premier event. Come check out handbags, shoes and accessories designed by Elaine Turner, Houston's well-known designer and entrepreneur extraordinaire.

Elaine Turner designs are sold in over 200 specialty shops and department stores. Locally, her shops are in Rice Village and at City Centre, with a shop in The Woodlands opening soon. Elaine recently opened a location in San Antonio's Alamo Heights and is preparing to open boutiques in Nashville and on Manhattan's Madison Avenue later this fall. That's not all—she plans to open seven to ten new stores next year and 50 within the next five years. Jewelry and sunglasses lines are also in the works, with a collection of belts and scarves to follow.

Get a jump on your holiday shopping, have fun and support HAPS!

### HOUSTON AREA PARKINSON SOCIETY

# TEAM HAPS

PD-IT'S NOT A SPRINT, IT'S A MARATHON

With less than four months to go, the Marathon season is in full swing. Runners and walkers around Houston and the world are getting ready to participate in the 2013 events with the 5K scheduled for Saturday, January 12<sup>th</sup> and Chevron Houston Marathon and Aramco Houston Half Marathon scheduled for Sunday, January 13<sup>th</sup>.

This year's impressive *Team HAPS* crew will be hitting the streets to raise awareness of Parkinson's. But we need your help. We want you to be a part of this year's team. Sign up with HAPS and get a free Marathon t-shirt. Set up a fundraising page and you can qualify for all kinds of incentives like dinner and theater tickets, Bi-plane rides, and the highly desired Apple iPad. Call the HAPS office for more information at 713-313-1621.

Special thanks to Gensler for hosting the sold-out golf tournament benefitting HAPS on Saturday, October 27<sup>th</sup> at the Wildcat Golf Club. Gensler is the renowned architecture firm that designed Houston Ballet's state-of-the-art Center for Dance where HAPS groups take place. We also thank Board member Jo Furr and her husband Jim, who is Managing Principal of Gensler's South Central Region, for their ongoing commitment to making a difference in the lives of those affected by Parkinson's and for helping make it possible for HAPS to be the recipient of the proceeds of this event.

## Gensler



## A Good Night's Sleep May Improve Working Memory Training in Parkinson's Disease

New research has shown that some people with Parkinson's disease (PD) can improve their working memory with specialized training, but only after a period of deep sleep at night. The study was published online August 20 in the journal *Brain*.

Working memory is the ability to actively store and manipulate information in the brain. Everyday tasks that require working memory include planning, problem solving, mental arithmetic and navigation. The mild cognitive impairment that can occur in Parkinson's disease can affect working memory, leading to difficulty performing everyday activities, such as being able to remember who called just after hanging up the phone. Recent research has shown that people can improve their working memory with specific training tasks. Scientists do not know exactly how it works, but brain imaging studies have shown that training can actually change connections between brain cells (or neurons).

Michael Scullin, Ph.D., at Emory University School of Medicine wondered whether deep sleep along with training could improve working memory for people with Parkinson's disease. To find out, Dr. Scullin and his colleagues studied 53 people with Parkinson's disease and 10 people with dementia with Lewy bodies (DLB), a related disorder with more severe cognitive impairments than PD. Forty-two of the people with PD were taking one or more dopaminergic medications such as levodopa, whereas 11 were not taking any dopaminergic medication. The study volunteers stayed in a sleep laboratory for 48 consecutive hours. In the daytime, they completed eight training sessions for working memory. They also underwent tests – during which they were asked to remember numbers, and recite them forward and backward – to test working memory and short-term memory. During the two nights of the study, the volunteers were connected to a machine, called a polysomnogram, which monitored aspects of their sleep such as sleep phase, breathing and leg movements.

### Results

- People with PD who were taking dopaminergic medication showed significant improvement in the working memory test, but not in the short-term memory test, from day one to day two. People with PD who were not taking dopaminergic medication and people with DLB showed no improvements in either the forward or backward test.
- The volunteers did not improve their scores from one test to another during the day. The improvement occurred in the test after which volunteers slept.
- Volunteers with the most improved working memory scores had more slow-wave deep sleep and higher oxygen levels as they slept.

### What Does It Mean?

Cognitive complaints are common among people with PD and in the general population as well. Unfortunately, medications have only a limited role in improving cognitive function. This study suggests that the combination of dopaminergic medication, nighttime slow-wave sleep, and nighttime oxygen levels can all enhance working memory training in people with PD.

This finding is very encouraging, suggesting that people with PD could benefit from training to improve working memory. To maximize the benefit, doctors should correct existing sleep disturbances, the study's authors say. For example, people with low oxygen levels as they sleep could use a device called a CPAP, or continuous positive airway pressure, to treat sleep apnea. This study assessed participants over 48 hours. Further research must be done to determine how long the effect of cognitive training could improve working memory in people with PD.

**Reference:** Scullin, M. K., Trotti, L. M., Wilson, A. G., Greer, S. A., Bliwise, D. L. (2012). Nocturnal sleep enhances working memory training in Parkinson's disease but not Lewy body dementia. *Brain*, doi: 10.1093/brain/aws192.

This article was originally published in the "Parkinson's Science News: What Does it Mean?" section of Parkinson's Disease Foundation (PDF) website. It is reprinted, in its entirety, with permission from PDF. For other science news, please visit [www.pdf.org/science\\_news](http://www.pdf.org/science_news).

## Newly Diagnosed Education Program

For those diagnosed with Parkinson's disease within the past 3 years.

**Presented by  
Dr. Kim Monday**

Saturday, November 3, 2012  
8:30 am—12:30 pm

Seating is limited, registration is required.

Please contact Kathleen Crist, LMSW  
713-626-7114 or [crist@hapsonline.org](mailto:crist@hapsonline.org) to register or for information

## DBS DISCUSSION GROUP

An educational program for individuals with Parkinson's who are considering or have undergone Deep Brain Stimulation Surgery

**Presented by**

**Dr. Joohi Jimenez-Shahed  
Dr. Ashwin Viswanathan**

Wednesday, November 7, 2012  
6:00—8:00 pm

For more information contact  
Kathleen Crist, LMSW at  
713-626-7114 or [crist@hapsonline.org](mailto:crist@hapsonline.org)

## WELCOME LEANN



Beginning October 1<sup>st</sup>, a familiar face will be back in the HAPS office as Leann Randolph, LMSW officially joins the organization as the new *Social Worker and Advocacy Outreach Coordinator*. You may remember Leann from her graduate social work internship during spring 2012. She will be taking over for Celeste Harris, LMSW who recently departed HAPS as her family was relocated to Pittsburgh. We will miss Celeste greatly, but welcome Leann with open arms.

Leann earned her undergraduate degree in social work in 2004 before graduating from Our Lady of the Lake in San Antonio, TX with a master in social work this May. She spent six years as a case manager for Montrose Counseling Center, has experience facilitating support groups and is proficient in American Sign Language. Welcome Leann!

**Don't forget!** You have until November 1<sup>st</sup> to complete the HAPS Program Evaluation form you received in last month's newsletter. If you haven't already submitted yours you can return it via mail to 2700 SW Freeway Houston, TX 77098, fax to 713-521-3964 or email to [info@hapsonline.org](mailto:info@hapsonline.org). If more forms are needed, contact the HAPS office at 713-626-7114. Your feedback is important!

## GROUP SPOTLIGHT

### Champions Forest Tai Chi

**Led by:** Terri Sharpe

**Average Attendance:** 10

**Fun Facts:** In Chinese philosophy and medicine there exists the concept of "chi", a vital force that animates the body. One of the goals in Tai Chi is to foster circulation of this "chi" within the body, and doing so can improve your health and vitality. Tai Chi is for the body, mind and spirit.

**Benefits:** Calming the mind, balance, motor control, regulating blood pressure, and mental focus while gently stretching muscles and limbering joints, massaging internal organs and increasing breathing capacity.



## Tai chi helps Parkinson's patients with balance and fall prevention

Exercise is important for a healthy lifestyle but it is also a key part of therapy, rehabilitation and disease management. For Parkinson's disease, exercise routines are often recommended to help maintain stability and the coordinated movements necessary for everyday living. An NIH-funded study, reported in the February 9, 2012 issue of the *New England Journal of Medicine*, evaluated three different forms of exercise – resistance training, stretching, and tai chi – and found that tai chi led to the greatest overall improvements in balance and stability for patients with mild to moderate Parkinson's disease.

Parkinson's disease is a movement disorder that is caused by the loss of brain cells which control coordinated and purposeful motions. This cell loss results in tremor, rigidity, slowed movement (known as bradykinesia) and impaired balance (postural instability). While some symptoms, such as tremor, at least benefit from drug therapy initially, the medications currently available to treat Parkinson's are not as effective in restoring balance. This is a special concern for Parkinson's patients because postural instability frequently leads to falls.

Several studies have demonstrated that resistance training, for instance with ankle weights or using weight-and-pulley machines, has positive effects on balance and gait. As a result, doctors often suggest exercise or prescribe physical therapy to address problems with instability.

Fuzhong Li, Ph.D., research scientist at the Oregon Research Institute in Eugene, was part of a team of researchers who, in 2007, published a pilot study showing that tai chi was a safe exercise for individuals with mild to moderate Parkinson's disease. "We had been using tai chi for balance training in healthy older adults," Dr. Li commented, "and older adults and patients with Parkinson's disease share some difficulties with falls."

Tai chi is a balance-based exercise that originated in China as a martial art. While there are many different styles, all are characterized by slow, relaxed and flowing movements. In both the pilot study and the recent *New England Journal of Medicine* study,

patients performed a tai chi routine designed to challenge patients' stability and address the balance and stability-related symptoms of Parkinson's. The routine included slow, intentional, controlled movements that maximized the swing time of arm and leg motions, and repeatedly incorporated gradual shifts of body weight from one side to another, varying the width of their base of support by standing with feet together or further apart.

With support from the NIH's National Institute of Neurological Disorders and Stroke (NINDS), Dr. Li and colleagues conducted a larger clinical trial to compare tai chi to resistance training and stretching. The study assigned a total of 195 patients with mild to moderate Parkinson's disease to one of three exercise groups: tai chi, resistance training, or stretching. Patients attended class twice a week for 24 weeks. The investigators assessed balance and movement control by testing how far patients could lean and shift their

center of gravity without losing balance, and how directly the patients could reach out to a target, with a minimum of extraneous movement.

After six months, the patients in the tai chi group showed the greatest amount of improvement in balance and stability. Furthermore, patients in the tai chi and resistance training

groups had a significantly fewer falls over the six month period compared to participants in the stretching group.

"There is a learning curve involved," Dr. Li noted, adding that improvement is seen after four to five months of continued practice twice a week, and this trend is similar to what he had noted in his studies of older people.

Dr. Li described tai chi as similar to resistance training, the more commonly recommended physical therapy, in that it requires repetitive movement. Tai chi, however, not only involves shifting a person's weight and center of gravity, but it is also practiced at a dramatically slow speed and greatly emphasizes intentional control of movement.

"In tai chi we emphasize very slow and intentional movement," Dr. Li commented. "That imposed a lot of



# CONTRIBUTIONS

We are extremely grateful to the following individuals for their generous support of HAPS. Without the continued support of our donors, none of our programs or services would be possible.

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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.*

Tai chi continued from page 6

challenge, especially to those in the tai chi group who were used to fast movement."

Dr. Li also noted that tai chi is very safe and can be performed without equipment and in limited space.

Beth-Anne Sieber, Ph.D., a program officer at NINDS, said that falls are a dangerous side effect of Parkinson's disease and commented on the significance of Dr. Li's work. "The key observation in Dr. Li's study is that a specifically designed sequence of tai chi movements improves postural stability and prevents falls for an extended period of time in persons with Parkinson's disease. In addition, tai chi sequences can be tailored to improve balance in a spectrum of patients with mild to moderate symptoms." Dr. Sieber also noted that this study is indicative of a growing interest in examining how physical activity may improve symptoms of

Parkinson's disease. Further research will provide additional information on ways in which physical activity can improve disease symptoms and quality of life for people with Parkinson's disease.

By Nicole J. Garbarini, Ph.D.

**\*Li, F. et al. "Tai chi and postural stability in patients with Parkinson's disease." *New England Journal of Medicine*. February 9, 2012. Volume 366(6), pages 511-9.**

***This article was reprinted in its entirety from the NIHDS website and was last modified May 10, 2012.***  
[http://www.ninds.nih.gov/news\\_and\\_events/news\\_articles/Li\\_TaiChi\\_and\\_PD.htm](http://www.ninds.nih.gov/news_and_events/news_articles/Li_TaiChi_and_PD.htm)

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