

JULY 2011

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CANCELED

**Summer Lecture Session
Sleep Well, live well.
New date to be
announced. Stay tuned...**

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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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It hurts...

By Nina Brown



Having been in almost constant pain for the last number of years, I can understand that when you are in pain, all you want is for someone to make it go away! I know I certainly didn't feel like writing about it, but none of us will get through life without experiencing some kind of pain. And, it happens that pain occurs twice as frequently in people with Parkinson's, with 40-50% of those experiencing aching, stiffness, numbness and tingling. Constant, aching pain and/or stiffness on one side of your body—usually in a shoulder, arm or leg—can be the first sign that you have Parkinson's. The inability to do fine movements with your fingers or dragging a foot can also be an indication.

Muscle rigidity, poor posture and gait contribute to a common type of pain called musculoskeletal pain which is usually felt as an ache around your joints, arms and legs, and may lead to muscle cramps and spasms. This pain is usually due to underlying arthritis or degenerative changes that are not due to Parkinson's, but certainly worsened by it. The pain stays in one place and does not move around or "shoot" down a leg or arm. This type of pain may need to be diagnosed with tests such as x-rays, bone scans, ultrasound or orthopedic consultation to determine the cause. A regular exercise program that emphasizes range of motion, along with pain medication prescribed by a doctor, might be helpful.

People with Parkinson's may experience painful muscle cramps resulting from involuntary contractions. Cramps may cause pain in the legs and calf muscles as well as restlessness, which, in turn, can cause you to lose sleep. Tonic water or tablets that contain quinine may help. Remember to also drink plenty of water because even mild dehydration can cause and back pain, fatigue and confusion.

Dystonia, a spasm causing sustained twisting or posturing in a group of muscles, can cause pain when your Parkinson's medications are wearing off at night and can cause your feet to turn inwards. Dystonia is different from rigidity. Although both make the muscles hard—with rigidity, the hardness results from the muscles becoming "less elastic" while with dystonia, the hardness results from the muscles contracting without relaxing.

Pain from dystonia is mostly related to "off" periods when Parkinson's medications are wearing off and moving is difficult. Making the "on" period last longer, can help with this kind of pain.

If you are one of the few who experience dystonic spasms such as facial grimacing or uncomfortable limb posturing, ask your neurologist if taking small and frequent doses of levodopa drugs, using a long-acting dopamine agonist drug, or combining levodopa with a COMT inhibitor such as entacapone might help.

A self-injectable drug called apomorphine may be used as a rescue therapy when meds have worn off suddenly or failed to kick in. This is sometimes used in the



Dr. Erin Furr-Stimming Assistant Professor of Neurology
Movement Disorders Division
Chief of Neurology, LBJGH UT Health
and member of the HAPS Medical
Advisory Board.

Q: What is DaTScan and what does this mean for me?

A: DAT is an abbreviation for the dopamine (DA) transporter (T). The DaTscan enables physicians to visualize DAT density in the brain. Parkinson's disease (PD) is a neurodegenerative disease fundamentally caused by the neuronal degeneration of the substantia nigra pars compacta (SNc). The cells located in the SNc produce and supply dopamine to the basal ganglia. Dopamine is a neurotransmitter that modulates movement. As a result of the decrease in dopamine production in PD patients, there is also a reduction of nerve terminals and DAT receptors. We use DAT density as a reliable marker for the integrity of one of the major dopamine pathways in the brain.

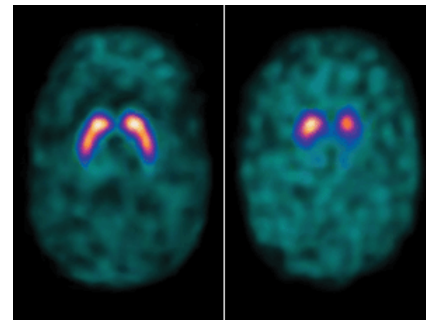
Since these changes cannot be visualized on routine neuroimaging, like a CT scan or MRI, DaTscan can be used. Ioflupane|123 injection, sold under the trade name DaTSCAN, is a radiopharmaceutical drug indicated for striatal dopamine transporter visualization using SPECT brain imaging to assist in the evaluation of adult patients with suspected Parkinsonian syndromes.

Three to six hours after the IV administration of Ioflupane|123, acquisition of images using a gamma camera is performed. The imaging usually takes between 30 to 45 minutes and is performed in the Nuclear Medicine department.

The difference between a normal and abnormal scan is primarily based on the visualization of structures in the brain called the caudate and putamen. In

Ask the Doctor

patients without PD, a transverse slice through the striatum shows a "comma shaped" putamen on each side and a circular shaped caudate. In patients with PD, a decrease in uptake in the putamen occurs while the caudate is preserved producing circular image.



Normal (left) and abnormal (right)
DaTScan results.

Diagnosing PD primarily relies on the neurologic exam preferably performed by a Movement Disorder Specialist. Unfortunately, this is an imperfect method, with only 90% accuracy. If the diagnosis is made in a non-specialized setting, only 76% of patients receive an accurate diagnosis. What does this mean for you? Using DaTscan can assist or improve diagnostic accuracy in those patients with an uncertain diagnosis. DaTscan has not proven to differentiate PD from atypical parkinsonian syndromes like Progressive Supranuclear Palsy (PSP) or Multiple Systems Atrophy (MSA); however, it does add value in distinguishing Parkinsonian versus non Parkinsonian tremors such as Essential Tremor. If you have been diagnosed with PD and are responding well to treatment with medications most likely a DaTscan would not add any meaningful value to your treatment.

Pain continued from page 1

mornings when symptoms of dystonia can be present, but can also be used throughout the day if off period symptoms, including pain, are particularly bothersome. Another treatment option for dystonia is botulinum toxin injections, a sort of local muscle relaxer that can relieve symptoms for up to three months.

If you have dyskinesia or abnormal involuntary movements related to Parkinson's, you may experience pain anywhere throughout the body. Occasionally, dyskinesia-related pain can happen between doses of Parkinson's. In these cases, the doses of relevant drugs may have to be reduced.

Radicular pain is a sharp, shooting pain that can feel like a shock that travels down a leg or an arm with tingling and numbness or a burning feeling in your toes and/or fingers. This type of pain is usually the result of a trapped nerve as it exits the spinal cord around the neck or back area and can be worsened by the twisting movements produced by severe dyskinesias or the stiffness of Parkinson's.

The discomfort from akathisia occurs from a sense of restlessness. This pain is mostly related to "off" periods. If you can make your "on" period last longer, it may reduce this kind of pain.

This article does not attempt to prescribe or recommend treatment. Only you can feel your pain. That's why it's important to know how to describe your pain to help your doctor understand the problem. Words you can use are: aching, biting, burning, cramping, gripping, hurting, pinching, ripping, stabbing and throbbing. Be specific about where it hurts the most. Use a scale of "0" to "10" to describe the severity of the pain? How long have you had the pain and how long does it last? Do certain positions make it better or worse? Does it seem to be an unusual pain such as one from a muscle spasm that radiates along a nerve? Pain from Parkinson's shouldn't be associated with discoloration, inflammation, redness, swelling or warmth of the skin.

In general, remember that reducing stress can lessen pain and other Parkinson's symptoms. Pain can result in sleep deprivation and cause depression to fluctuate and worsen. Parkinson's might not be the reason for all your pain, but since pain can be one of the most disabling symptoms experienced, it is important to address it with your physician and try to manage it.

Summer Lecture Series

**July 13th
10:00—11:30 AM**

Love and other drugs in PD: what you need to know but can't learn from the movies.



**CANCELED
New Date- TBA**

Sleep well, live well: understanding the connection between sleep and PD.

**August 24th
6:30—8:00 PM**

Bridging the communication divide: strategies and treatment options.

Sessions will be held at the American Red Cross Building, 2700 SW Freeway.

Shop for haps

KROGER NEIGHBOR TO NEIGHBOR PROGRAM

1% of your grocery purchases can be donated to HAPS every time you shop. Each July, you must re-enroll in the program. To enroll for the current year, take this barcode along with your Kroger Plus Card to your Kroger store cashier to scan. Or present the barcode and the phone number associated with your Kroger Plus Card to the cashier and you will be enrolled for the next 12 months.



Randalls Good neighbor program

Randalls will donate 1% of your grocery purchases to HAPS every time you shop. Take this card along with your Remarkable Card to the customer service desk at Randalls. They will link your card to the HAPS Good Neighbor number—it's that easy!



HAPS PD EXERCISE AND SUPPORT GROUPS

CENTRAL

PD & DEMENTIA/ LEWY BODY DEMENTIA CAREGIVER SUPPORT GROUP	4th Monday of month 10:30 am—12:15 pm	Support group for caregivers of persons with Parkinson's and dementia or Lewy Body Dementia	For more information Kathleen Crist, LMSW 713-626-7114
WATER EXERCISE	Mondays 1:00—2:00 pm Thursdays 11:00 am—12:00 noon	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	For more information and to request participant paperwork Alfonso Hernandez 713-520-8670
EXERCISE	Tuesdays 3:30—4:30 pm	TIRR 2455 S. Braeswood Houston, TX 77030	For more information Alfonso Hernandez 713-520-8670
SPEECH & EXERCISE	Wednesdays 2:30—4:00 pm	Memorial Dr. Presbyterian Church 11612 Memorial Drive—The Parlor Houston, TX 77024	For more information Alfonso Hernandez 713-520-8670
YOUNG ONSET SUPPORT GROUP	2nd Wednesday of month 7:00—9:00 pm	For those younger than 55 with Parkinson's disease	For more information Kathleen Crist, LMSW 713-626-7114
TAI CHI	Tuesdays 10:30—11:30 am	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	For more information Alfonso Hernandez 713-520-8670
TANGO	Wednesdays 1:00—2:15 pm	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	For more information Kathleen Crist, LMSW 713-626-7114
DANCE	Mondays 12:45—2:00 pm	Houston Ballet Center for Dance 610 Preston Houston, TX 77002	For more information Kathleen Crist, LMSW 713-626-7114
SINGING	2nd Monday of month 12:00—1:00 pm	Houston Ballet Center for Dance 610 Preston Houston, TX 77002	For more information Kathleen Crist, LMSW 713-626-7114
EXERCISE	Thursdays 9:45—10:45 am	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	For more information Alfonso Hernandez 713-520-8670
POST DBS SUPPORT GROUP	4th Wednesday of every other month 6:00—7:30pm	For those who have completed Deep Brain Stimulation Surgery	For more information Kathleen Crist, LMSW 713-626-7114
 NEW PD SUPPORT GROUP	3rd Tuesday of month 10:00—11:30 am	American Red Cross 2700 SW Freeway Houston, TX 77098	For more information Kathleen Crist, LMSW 713-626-7114
TAI CHI	Fridays 11:00 am—12:00 noon	Memorial Dr. Presbyterian Church 11612 Memorial Drive—Room 102 Houston, TX 77024	For more information Alfonso Hernandez 713-520-8670

SOUTH

EXERCISE & SPEECH	Mondays Speech 3:30—4:15 pm Exercise 4:15—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
WATER EXERCISE	Thursdays 4:00—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
CAREGIVER SUPPORT GROUP	3rd Monday of month 4:00—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Kathleen Crist, LMSW 713-626-7114
EXERCISE	Wednesdays 4:00—5:00 pm	St. Andrew's Episcopal Church 2535 E. Broadway, FM 518 Pearland, TX 77581	For more information Alfonso Hernandez 713-520-8670

EAST

WATER EXERCISE	Tuesdays Thursdays 2:00—3:00 pm	Bay Area Rehabilitation Center 3513 Decker Drive Baytown, TX 77520	For more information Alfonso Hernandez 713-520-8670
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**ALL GROUPS ARE FREE OF CHARGE—PLEASE VISIT THE WEBSITE AT WWW.HAPSONLINE.ORG OR
CALL TO CONFIRM GROUP TIMES AND LOCATIONS**

SOUTHEAST

SPEECH & EXERCISE	Tuesdays Speech 1:30—2:00 pm Exercise 2:00—3:00 pm	Kindred Hospital Bay Area 4801 E Sam Houston Parkway Pasadena, TX 77505	For more information Alfonso Hernandez 713-520-8670
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SOUTHWEST

EXERCISE	Mondays 10:00—11:00 am	First United Methodist Church 1220 FM 1092 Missouri City, TX 77459	For more information Alfonso Hernandez 713-520-8670
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EXERCISE	Tuesdays 2:00—2:45 pm	St. Phillip's Methodist Church 5501 Beechnut (Fellowship Hall) Houston, TX 77096	For more information Alfonso Hernandez 713-520-8670
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MUSIC	Fridays 10:00—11:00 am	Space is limited. Please call to register.	For more information Alfonso Hernandez 713-520-8670
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PROGRESSIVE SUPRANUCLEAR PALSY SUPPORT GROUP	3rd Saturday of month 1:00 pm	Memorial Hermann SW Houston Prof Building II - Learning Center B Hwy 59 at Beechnut Houston 77074	For more information Karen Kennemer 281-358-2282
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WEST

SPEECH & EXERCISE	Tuesdays Speech 5:20—6:05 pm Exercise 6:05—6:50 pm	1st United Methodist Church of Katy 5601 5th Street Room 111 Katy, TX 77493	For more information Alfonso Hernandez 713-520-8670
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CAREGIVER SUPPORT GROUP	Please Call	1st United Methodist Church of Katy 5601 5th Street Room 107 Katy, TX 77493	For more information Kathleen Crist, LMSW 713-626-7114
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NORTHEAST

EXERCISE	Wednesdays 12:00 noon—1:00 pm	HealthSouth Rehabilitation Hospital 19002 McKay Blvd. Humble, TX 77338	For more information Alfonso Hernandez 713-520-8670
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NORTH

WATER EXERCISE	Mondays 12:30—1:30 pm	Reliant Rehab Hospital N Houston 117 Vision Park Blvd. Shenandoah, TX 77384	For more information Alfonso Hernandez 713-520-8670
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SPEECH	Tuesdays 1:45—2:30 pm	Reliant Rehab Hospital N Houston 117 Vision Park Blvd. Shenandoah, TX 77384	For more information Alfonso Hernandez 713-520-8670
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EXERCISE & TAI CHI	1st, 3rd, 5th Thursdays 1:30—2:30 pm 2nd, 4th Thursdays	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	For more information Alfonso Hernandez 713-520-8670
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CAREGIVER SUPPORT GROUP	1st Thursday of month 1:30—2:30 pm	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	For more information Kathleen Crist, LMSW 713-626-7114
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DANCE & SINGING	Call for Summer Schedule 12:00—2:00 pm	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	For more information Alfonso Hernandez 713-520-8670
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NORTHWEST

TAI CHI	Fridays 11:00—12:00 noon	Tomball United Methodist Church 1603 Baker Drive (Faith Building) Tomball, TX 77375	For more information Alfonso Hernandez 713-520-8670
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TAI CHI	Wednesdays 10:00—11:00 am	John Wesley United Methodist Church 5830 Bermuda Dunes (Boy Scout Building) Houston, TX 77069	For more information Alfonso Hernandez 713-520-8670
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SPEECH	Thursdays 1:00—2:00 pm	TEAM Approach Speech Therapy Center 11240 FM 1960 W. Suite 209 Houston, TX 77065	For more information Alfonso Hernandez 713-520-8670
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CROSSROADS GROUP	2nd Wednesday of every other month 7:00—9:00 pm	For individuals with PD between age 55 and 70.	For more information Kathleen Crist, LMSW 713-626-7114
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HAPS Argentine Tango Class—Shall we dance?

By Joan Bishop, HAPS Tango Instructor



Documented in-depth research has revealed that of all the partner dances, Argentine Tango is the most beneficial for improving the balance of those who have been diagnosed with Parkinson's. The first heightened sensation that all students of Argentine Tango report is enhanced bodily awareness. In addition, students acquire a deeper understanding of the results of movements related both to the music and to their partners. The focus of instruction is on "leading" and "following," which enables everyone to dance together. Social interaction among students during the learning process develops a sense of camaraderie and accomplishment. Dance parties called Milongas provide opportunities to take Argentine Tango to the social dance floor.

The HAPS Argentine Tango Class dancers have named our periodic dance event, *Milonga of the Open Heart*. Tango music CDs are given as classroom material, and students are strongly encouraged to listen to the music outside of class. The tango pieces played at each Milonga are selected by a vote of the students. Participants learn to listen corporally to this multi-dimensional music called "Tango" — both as leaders and as followers — and to create their own dance within the framework of the Argentine Tango vocabulary. Leaders develop the skills to invite their followers to take steps different from the leader's steps, thereby improving not only their left and right-brain functions but also their musicality.



Exercises and skills learned in class relate directly to improved posture and balance, the ability to adapt to one's partner in the dance, and the ability to adapt to one's surroundings in a more sensitive manner — resulting in fewer falls and an enhanced ability to apply learned movements to everyday life. Examples are: navigation (such as weight shifts while turning in a small area) which results in an ability to be seated with greater ease; and, isolation between the upper and lower body for improved balance, carriage, and foot placement, all of which result in an ability to walk more confidently.

Learning is always exciting; this is especially true when it builds fond memories. It is doubly exciting when what we learn can be applied to improve the quality of our daily lives. By learning how to better control our movements, we gain greater individual confidence, as well as receive the added bonus of exercise — all while participating within a welcoming group.



We change partners frequently during classes, and individual attention is given to direct each student in tailoring their dance to their range of motion. Through leading and following techniques acquired in HAPS Argentine Tango group classes, students learn to create their own dance and to live in the moment through the music and their partners.

Our goals are to have fun while making progress. Participants are encouraged to reframe their goals in terms of physical improvement by tackling new challenges in small repetitive pieces. Particular and continuing emphasis is placed upon students' realization that it is through mistakes that all of us learn ... and this enables class

members to progress at their own pace without embarrassment, any fear of being judged, or fear of failure. The desire to improve is all that any student needs.

If you are interested in participating in the HAPS Argentine Tango group dance class, call the HAPS office, 713-520-8670. Beginners are welcome, and no partner is required. We look forward to seeing you on the dance floor.

Humble PD Support Group

beginning August 2011

First United Methodist Church of Humble
800 East Main
Humble, TX 77338

4th Wednesday of the month from 6:30-7:30 PM
If you are interested in attending, call 713-626-7114

Thank You!

Many thanks to Dr. Joohi Jimenez-Shahed, HAPS Medical Advisory Board member, who led the presentation of the Newly Diagnosed Education Program, Saturday, June 25th. We appreciate your time and expertise.

NEW

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.

GIFTS

Hilda Cardenas	Janet and Robert Geosits
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NINDS Stops Coenzyme Q10 Trial

On May 27th, The National Institute for Neurological Disease and Stroke (NINDS) announced that they have, stopped the phase III clinical trial of Coenzyme Q10, known as the QE3 study. The study was designed to test whether high doses of Coenzyme Q10(CoQ10) had a neuroprotective effect by slowing the progression of Parkinson's disease in those with early PD. Trial investigators have not found any safety concerns related to CoQ10 at dosages of 1200mg/day and 2400mg/day of treatment. However, they determined that there was not enough statistically significant data to show neuroprotective or symptomatic benefit related to use of Coenzyme Q10 to continue the study.

This is a disappointing ending to the many who were hopeful that use of CoQ10 would result in benefits for Parkinson's disease. CoQ10, an over-the-counter supplement, is an antioxidant which has an important role in mitochondrial function. Oxidative stress and mitochondrial dysfunction have both been implicated as contributors to Parkinson's disease.

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