

APRIL 2010

HAPS Annual Educational Symposium

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MARK YOUR CALENDARS

2nd World Parkinson Congress
Sept 28– Oct 1, 2010
Glasgow, Scotland

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

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Saturday, April 24, 2010

10:00 am—2:45 pm

United Way

50 Waugh Drive

Houston, TX 77007

April is Parkinson's Disease Awareness Month and in recognition of that, it is a time when HAPS traditionally hosts its Annual Educational Symposium. This year's event, **"Approaching Parkinson's Creatively: New Treatments for a New Decade,"** will provide opportunities for those who attend to put into practice the innovative, self-determined approaches to managing PD featured in the 2009 Annual Educational Symposium that HAPS presented in partnership with the Parkinson's Disease Foundation.

These experiential, interactive workshops offer the chance to participate in activities you may have read about and not yet tried. Sessions include dance, singing, tango, art and Wii therapy. The symposium includes lunch and is free of charge. Space is limited so you must pre-register to attend. We hope you will join us!

For more information on the 2010 Symposium, see page 3.



ASK THE ADVOCATE

Q. Why is H.R. 1362/S. 1273 so important to the Parkinson's community?

A. H.R. 1362/S. 1273 is the National MS and Parkinson's Disease Registries Act. This legislation authorizes \$5,000,000 over five years to establish national Multiple Sclerosis (MS) and Parkinson's disease (PD) registries that will determine the incidence and prevalence of the diseases and lay a foundation for better evaluating and understanding these diseases over time.

Currently, we don't have accurate information regarding how many Americans are battling Parkinson's disease and why. This lack of core knowledge inhibits Parkinson's research, programs, treatments and services. At a minimum, accurate information about the incidence and prevalence of Parkinson's disease will assist in planning future healthcare needs, detect changes in health practices, assess disease burden, promote advocacy and support a wide range of research initiatives, and will facilitate future research that may lead to discovery of breakthrough treatments — and one day a cure for PD.

This legislation requires the Agency for Toxic Substances and Disease Registry (ATSDR) at the Centers for Disease Control and Prevention (CDC) to develop coordinated, separate national systems to collect and store existing MS and PD data on incidence and prevalence. To develop the registries, the CDC will use a methodology that relies on information from existing databases such as Medicare, Medicaid, the Department of Veterans Affairs, state registries, pharmacy databases, death certificates and medical institutions. ATSDR will follow relevant privacy laws and regulations, and it will coordinate with other Federal agencies, including sharing any epidemiological findings.

The data collected will include geographical information, age, race or ethnicity, gender, military service and family history of individuals who are diagnosed with the diseases. The information gathered through the registries will provide a foundation for evaluating and understanding many disease factors such as geographic clusters of diagnoses and variances in the gender ratio, and will give us the ability to examine changes over time such as an increasing rate of young-onset Parkinson's disease. The MS and Parkinson's registries may help uncover and inform promising areas of research like genetic and environmental risk factors, and the resulting data could be used to provide consistency and coordination in addressing treatment of disease nationwide.

The bill also creates an Advisory Committee on Neurological Disease Registries (Advisory Committee). The Advisory Committee will be comprised of experts and stakeholders from ATSDR, National Institutes of Health, Food and Drug Administration, Department of Veterans Affairs and Department of Defense, as well as people living with MS and Parkinson's disease, clinicians, researchers and voluntary health associations. The Committee will make recommendations to the Secretary of Health and Human Services on how to:

- Implement and maintain the MS and Parkinson's registries
- Use and make available the registries' data, including guidelines for such use
- Develop additional registries for other neurological disorders based on the MS and PD registries

For more information on how you can get involved in supporting this important piece of legislation go to www.parkinsonsaction.org or contact the HAPS office for more information 713-626-7114.

HAPS Annual Educational Symposium

Saturday, April 24, 2010

KEYNOTE SPEAKER

"LAUGHING" LAURA GENTRY

CERTIFIED LAUGHTER YOGA INSTRUCTOR



Laughter Yoga combines Yogic breathing with unconditional laughter. This technique is based on the scientific fact that the body cannot differentiate between forced, fake laughter and real laughter. The physiological and psychological benefits are the same: reduced stress, lowered blood pressure, strengthened immune system, decreased physical pain, improved mood and increased happiness.

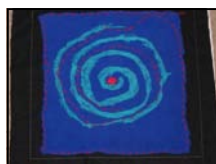
Approaching Parkinson's Creatively: New Treatments for a New Decade

10:00	Check In
10:15	Introduction
10:20	Keynote Speaker
11:20	Lunch
12:00	Breakout Session I (45 minutes)
1:00	Breakout Session II (45 minutes)
2:00	Breakout Session III (45 minutes)
2:45	Adjourn



Susan Murray

BREAKOUT SESSIONS



Judi Jecmen



Annelies Massey

ART It is believed that creating art can help people cope with the stress and symptoms of chronic illness and improve one's cognitive abilities. This workshop gives you the opportunity to express yourself creatively and contribute to the Parkinson's Disease Foundation's *Quilt Project* designed to raise awareness of the impact the disease has on people's lives. The quilt will consist of panels made by individuals and groups affected by PD in honor of the cause or their group or their loved ones living with Parkinson's disease and will be displayed at the 2nd World Parkinson Congress Sept 28–Oct 1, 2010 in Glasgow, Scotland. No art experience necessary!

DANCE If you want to give dance a try and haven't been able to attend the HAPS/Houston Ballet *Dance for Parkinson's* class, this is your chance! Studies have shown that dance can have a rehabilitative effect on movement and social dance in a group setting can motivate people to move and have fun. Led by former Houston Ballet principal dancer and HAPS *Dance for Parkinson's* instructor Krissy Richmond.

SINGING Research has shown that vocal exercise can increase voice volume in people with Parkinson's. Singing can be both physically and emotionally invigorating, especially when experienced with others who share the same incentive and enthusiasm. If you like singing and live piano music or if you just want to try a creative vocal exercise, this session is for you.

TANGO Does it take two to tango or just a willingness to try something new and have fun? Tango uses many aspects of movement that are especially relevant to those with Parkinson's disease including turning, initiation of movement, balance, moving at a variety of speeds and walking backwards. Recent research has proven that tango can be a beneficial therapy for people affected by PD. If you haven't had the chance to try the HAPS tango class, now is the time to give it a twirl! Led by HAPS tango instructor Antje Kalinauskas who is an expert in Argentine Tango dance.



Wii-HABILITATION The use of virtual reality and games as therapeutic tools is on the rise. Together, they provide a controlled physical environment that is safe and fun. The Wii (pronounced "we") gaming system with games like bowling, boxing and tennis improves visual perception, hand-eye coordination and sequenced movement. Come on, let's have a game!

HOW TO REGISTER—Complete the registration form enclosed in this newsletter indicating your 1st, 2nd and 3rd choice of breakout session workshops and return to the HAPS office by April 19th. One form per person. Please make copies for additional participants.

HAPS PD EXERCISE AND SUPPORT GROUPS

ALL GROUPS ARE FREE OF CHARGE—PLEASE CALL TO CONFIRM GROUP TIMES AND LOCATIONS

CENTRAL

PD & DEMENTIA/ LEWY BODY DEMENTIA CAREGIVER SUPPORT GROUP	4th Monday of month 10:30 am—12:15 pm	Support group specifically for caregivers of persons with Parkinson's and dementia	For more information and to see if this group is appropriate for you Kathleen Crist, LMSW 713-626-7114
WATER EXERCISE	Mondays 2:00– 3:00 pm Thursdays 11:00 am—12:00 noon	W. Gray Adaptive Recreation 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 Dr. Room 102 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 Celeste Harris, LMSW 713-313-1621
TAI CHI	Tuesdays 10:30—11:30 am	W. Gray Adaptive Recreation Center 1475 West Gray Houston, TX 77019	For more information Alfonso Hernandez 713-520-8670
TANGO	Wednesdays 1:00-2:15 pm	W. Gray Adaptive Recreation 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 Academy 1921 West Bell Street Houston, TX 77019	For more information Kathleen Crist, LMSW 713-626-7114
EXERCISE	Thursdays 9:30—10:30 am	W. Gray Adaptive Recreation Center 1475 West Gray Houston, TX 77019	For more information Alfonso Hernandez 713-520-8670
POST DBS SUPPORT GROUP	4th Tuesdays of every other month 6:00—7:30pm	For those who have completed Deep Brain Stimulation Surgery	For more information Celeste Harris, LMSW 713-313-1621
TAI CHI	Fridays 11:00 am—12:00 noon	Memorial Dr. Presbyterian Church 11612 Memorial Dr. Room 102 Houston, TX 77024	For more information Alfonso Hernandez 713-520-8670

SOUTH

EXERCISE & SPEECH	Mondays Exercise 9:00—9:45 am Speech 9:45– 10:30 am	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
WATER EXERCISE	Thursdays 12:00—1:00 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	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Celeste Harris, LMSW 713-313-1621
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 7 Swalm Center Drive Baytown, TX 77520	For more information Alfonso Hernandez 713-520-8670
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HAPS PD EXERCISE AND SUPPORT GROUPS

GROUP SCHEDULES CAN ALSO BE VIEWED ON THE WEBSITE AT WWW.HAPSONLINE.ORG

SOUTHEAST

SPEECH & EXERCISE	Tuesdays Speech 1:30—2:00 pm Exercise 2:00—3:00 pm	Kindred Bay Area Hospital 1004 Seymour Street Pasadena, TX 77506	For more information Alfonso Hernandez 713-520-8670
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SOUTHWEST

EXERCISE	Mondays 10:00 –11:00 a,	First United Methodist Church 1220 FM 1092 Missouri City, TX 77459	For more information Alfonso Hernandez 713-520-8670
SPEECH & EXERCISE	Tuesdays Exercise 2:00—2:45 pm Speech 2:45-3:45 pm	St. Phillips Methodist Church 5501 Beechnut Room 104 Houston, TX 77096	For more information Alfonso Hernandez 713-520-8670
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

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
CAREGIVER SUPPORT GROUP	3rd Tuesday	1st United Methodist Church of Katy 5601 5th Street Room 107 Katy, TX 77493	For more information Celeste Harris, LMSW 713-313-1621

NORTHEAST

EXERCISE	Wednesdays 10:00— 11:00 am	First United Methodist of Humble 800 East Main Humble, TX 77338	For more information Alfonso Hernandez 713-520-8670
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NORTH

WATER EXERCISE	Mondays 12:00 noon—1:00 pm	HealthSouth 18550 IH 45 S Conroe, TX 77384	For more information Alfonso Hernandez 713-520-8670
EXERCISE & TAI CHI	1st, 3rd, 5th Thursdays 1:30—2:30 pm 2nd, 4th Thursdays	Woodlands United Methodist Church 2200 Lake Woodlands Drive (Aldersgate Hall) The Woodlands, TX 77380	For more information Alfonso Hernandez 713-520-8670
CAREGIVER SUPPORT GROUP	1st Thursday of month	Woodlands United Methodist Church 2200 Lake Woodlands Drive (Aldersgate Hall) The Woodlands, TX 77380	For more information Kathleen Crist, LMSW 713-626-7114

NORTHWEST

EXERCISE	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
CAREGIVER SUPPORT GROUP	Please call	Tomball United Methodist Church 1603 Baker Drive (Faith Building) Tomball, TX 77375	For more information Celeste Harris, LMSW 713-313-1621
SPEECH	Thursdays 10:00—11:00 am	Foundry—A United Methodist Congregation 8350 Jones Road (Scout Building) Houston, TX 77065	For more information Alfonso Hernandez 713-520-8670
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 Celeste Harris, LMSW 713-313-1621

Parkinson's U.S. rates highest in whites, Hispanics, and Midwest, Northeast

By Michael C. Purdy ▪ January 27, 2010

Reprinted in its entirety with permission from Washington University School of Medicine, St. Louis, MO

"Finding clusters in the Midwest and the Northeast is particularly exciting."

The largest epidemiological study of Parkinson's disease in the United States has found that the disease is more common in the Midwest and the Northeast and is twice as likely to strike whites and Hispanics as blacks and Asians. The study, based on data from 36 million Medicare recipients, is both the first to produce any significant information on patterns of Parkinson's disease in minorities and to show geographic clusters for the condition.

"Finding clusters in the Midwest and the Northeast is particularly exciting," says lead author Allison Wright Willis, M.D., assistant professor of neurology at Washington University School of Medicine in St. Louis. "These are the two regions of the country most involved in metal processing and agriculture, and chemicals used in these fields are the strongest potential environmental risk factors for Parkinson's disease that we've identified so far." The results appear online in the journal *Neuroepidemiology*.

"...chemicals used in these fields are the strongest potential environmental risk factors for Parkinson's disease that we've identified so far."

Parkinson's disease is a common neurodegenerative condition that causes tremor, stiffness, slowness, mood and behavioral disorders, sleep problems and other symptoms. The disease is characterized by loss of dopamine, a compound involved in communication between brain cells. According to Willis, genetic factors explain only a small percent of cases. Environmental factors are likely more common contributors and may include prolonged exposures to herbicides and insecticides used in farming or to metals such as copper, manganese and lead.

For the new study, Willis analyzed data on more than 450,000 cases of Parkinson's disease per year over six years, 1995 and 2000-2005. Collectively, that data included information from more than 98 percent of all Americans 65 and older. Willis found Asians and blacks developed Parkinson's disease at half the rate of whites and Hispanics. "We are going to try to learn more about why this is the case," Willis says. "It could be that those with Asian or African ancestry have genes that help protect them from exposure to environmental factors that cause Parkinson's disease, or they may have fewer exposures to those factors."

"This was the largest descriptive epidemiological study yet to be conducted of Parkinson's disease in the United States ..."

Epidemiologists have long debated whether Parkinson's disease is more prevalent in rural or urban areas, with some studies showing higher rates in cities and some in the countryside. Willis found the condition is more common in urban areas but concluded the comparison between the two rates offered little potential for insight into the disease. "It's always been an open question as to how to best define the terms 'urban' and 'rural'," Willis says. "Urban and rural is defined in many different and relatively arbitrary ways, and we came away convinced by our results that these distinctions have little to do with what is causing the disease."

Willis and her colleagues plan further studies of how exposure to single or combined environmental factors influences disease risk. "This was the largest descriptive epidemiological study yet to be conducted of Parkinson's disease in the United States, and it has both given us some interesting new leads for the future research and reinforced some ideas we already had," Willis says.

CONTRIBUTIONS

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HEALTH CARE REFORM UPDATE:

Sunday, March 21, 2010, the United States House of Representatives approved historic health care reform legislation by passing both the *Patient Protection and Affordable Care Act* and the *Health Care and Education Reconciliation Act of 2010 (Reconciliation Bill)*. While this legislation has been plagued with controversy and debate, and people seem to have their own opinions about the bill, there are several provisions that are of interest to the Parkinson's community:

- Creating a Cures Acceleration Network (CAN) at the National Institutes of Health which enables fast-tracking therapies and drugs for Parkinson's and other diseases
- Extending Medicare Therapy Caps exceptions process until December 31, 2010 for medically necessary outpatient occupational, physical and speech therapy
- Eliminating lifetime caps on benefits for all insurance plans six months after enactment of the bill
- Eliminating annual caps on benefits for individual and group plans in 2014
- Closing the Medicare Part D donut hole by 2020, and providing a \$250 rebate for all Medicare Part D enrollees who enter the donut hole in 2010
- Prohibiting insurers from establishing eligibility rules based on health status, medical condition, claims experience, receipt of healthcare, medical history, genetic information, evidence of insurability, disability, etc.

President Obama signed the *Patient Protection and Affordable Care Act* into law on Tuesday, March 23rd. Congress finished its work on the *Reconciliation Bill* which will go to the President for his signature - completing their work on health care reform.

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