

AUGUST 2011

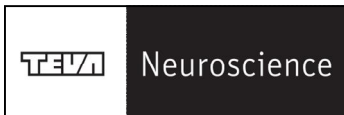
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Check out the new HAPS groups!
More info on page 3.

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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Parkinson's Research and You

For those of you who have heard the words, “You have Parkinson’s,” it is likely that you experienced feelings of disbelief, numbness, bewilderment or, possibly, relief. The first time you told someone else, “I have Parkinson’s,” it is probable that they felt the same way. You are doing your best to stay on top of this disease by taking your medications, educating yourself, working with your physician, exercising and coping with a positive attitude, but you may feel like you could be doing more. Often families and friends feel the same way. They can offer help and support, yet, many times feel powerless and want to do something that feels more meaningful.

Recently, there has been a great push and much focus on fast-tracking Parkinson’s disease (PD) research while giving members of the Parkinson’s community many important opportunities to get involved. Any of us can take part in these research initiatives dedicated to accelerating available treatments and, ultimately, finding a cure for PD.

So, what can you do? How can you get connected, take part and affect meaningful change? Becoming an advocate or funding research are traditional methods of getting involved. But if you are looking for

something beyond advocating or writing a check—here are four specific ways to roll up your sleeves and get started.

If you have recently been diagnosed and are not currently taking standard PD medications, or if you do not have Parkinson’s and do not have a first-degree relative (parent, child or sibling) with PD, you might be interested in the **Parkinson’s Progression Markers Initiative (PPMI)**. Sponsored by the Michael

J. Fox Foundation for Parkinson’s Research, PPMI is an ambitious, five-year research study. The study is being conducted in 21 locations throughout

the United States and Europe and is seeking 400 individuals with PD as participants and 200 control participants without PD. The Baylor College of Medicine Parkinson’s Disease Center and Movement Disorders Clinic in Houston is one of the 16 sites participating in PPMI in the United States.

The goal of the PPMI study is to identify one or more biomarkers of Parkinson’s disease progression. A biomarker is a substance or characteristic in our bodies that is associated with the presence of disease, or that changes over time in a way that can be linked to the progression of disease. Identifying biomarkers is crucial to the

“ We all have questions. Now you can be part of the answer.”

- Michael J. Fox

Research Continued page 2

development of new treatments for Parkinson's, particularly, treatments that could slow or stop the progression of the disease. The PPMI study is an observational study. This means that participants will not be given any type of experimental drug or treatment, but will undergo numerous tests and assessments related to PD. Imaging techniques, and the collection of blood, urine and spinal fluid will also be used.

You do not have to be a patient at the Parkinson's Disease Center and Movement Disorders Clinic at Baylor College of Medicine to participate in the PPMI study. Once enrolled, you may continue to see your physician of choice who will be made aware of your participation in this study. For more information on PPMI at Baylor College of Medicine contact Christine Hunter, RN, at 713-798-3951 or chunter@bcm.edu.

If you don't qualify for the PPMI study, there are still ways that you can get involved. July 14th, the Michael J. Fox Foundation for Parkinson's Research launched its beta version of the **Fox Trial Finder**, a Web-based solution designed to connect willing volunteers, both those with PD and those without, to Parkinson's clinical trials in need of participants. All you have to do is go online and register. The program collects your confidential information and matches currently available trials for which you qualify based on the information you provide. Even if there are no current trial matches, your information will be saved and you will receive email alerts when new trials with matching characteristics begin recruiting. Go to www.foxtrialfinder.org for more information.

PDtrials is a collaborative initiative led by Parkinson's Disease Foundation that includes Parkinson's organizations dedicated to increasing education and awareness of clinical trials. PDtrials aims to provide information about clinical research in general, such as who funds clinical trials and how clinical trials evolve, and it provides information and updates on PD clinical trials currently taking place throughout the United States.

PDtrials will help you learn what you need to know before making the decision to join a clinical trial and what to expect once you are enrolled. To learn more about PDtrials go to www.pdtrials.org.

If you would like to get involved in improving the process that leads to new Parkinson's therapies, you can make a difference by becoming a research advocate through the Parkinson's Disease Foundation's **Parkinson's Advocates in Research (PAIR)**. PAIR is dedicated to bringing educated community voices to important issues in PD research. Research Advocates participate in a three-day training program called the Clinical Research Learning Institute, where they are trained by leading clinical research experts and former Learning Institute graduates. The three-day training will help you become more familiar with the science of Parkinson's disease and understand the clinical research process. You will gain the leadership and advocacy skills to confidently interact with the scientific community and influence research decision-making. As a Research Advocate you can put your skills to work speaking at educational conferences and support groups on the importance of clinical research and study participation. You can serve on scientific review committees and clinical research advisory boards. In addition, you can review and comment on clinical research study design and protocol, the informed consent process, and enrollment strategies. To find out more about Parkinson's Advocates in Research and the Clinical Research Learning Institute, call 1-800-457-6676 or go online at www.pdf.org/pair.

Do not discount the role that individuals living with PD, friends and family members can play in the field of Parkinson's research. You have the power to make things happen. You can help move Parkinson's research forward and make a significant difference in the treatment of PD, and help science get closer to finding a cure.

By Kathleen Crist, LMSW



Save the Date 10.16.2011

Houston Area Parkinson Society

Presents

CHANGING *the face of* PARKINSON'S Annual Awards Event 2011

6 p.m. at The Bayou Club

Awards presentation, dinner & dancing
to the sounds of The El Orbits

Honoring

George & Mary Josephine Hamman Foundation
Michael "Rich" Clifford

Co-Chairs

Gail & Mike Hendryx
Leslye & David Weaver

More Information

Call 713.313.1621 or
visit www.hapsonline.org



MOVING FORWARD

January 15, 2012

HAPS is an official
Chevron Houston Marathon
Run for a Reason charity

For information on how you can show
your team spirit go to
www.hapsonline.org or call Elizabeth
at 713-313-1621

New HAPS groups...

Humble PD Support Group

beginning August 24th

**4th Wednesday of the month
6:30-7:30 PM**

First United Methodist
Church of Humble
800 East Main
Humble, TX 77338
Room 220 (above the main office)

Parking is located next to the
church office or in the small lot
off of Avenue G.

For more information call 713-626-7114
or email crist@hapsonline.org

NEWLY DIAGNOSED SUPPORT GROUP

New support group for
individuals who have been
diagnosed with Parkinson's
within the past three years.

**3rd Monday of the month
6:30-7:30 PM**

For more information or
if you are interested in attending,
call 713-626-7114 or email
crist@hapsonline.org

Exercise Group in Alvin

Beginning September 1st

**Thursdays
4:00-5:00 PM**


Alvin Lutheran Church
1800 FM 1462
Alvin, TX 77512

For more information call
713-520-8670 or email
hernandez@hapsonline.org

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 for caregivers of persons with Parkinson's and dementia or Lewy Body Dementia	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	To request participant paperwork Alfonso Hernandez 713-520-8670
EXERCISE	Tuesdays 3:30—4:30 pm	TIRR 2455 S. Braeswood Houston, TX 77030	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	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	Kathleen Crist, LMSW 713-626-7114
TAI CHI	Tuesdays 10:30—11:30 am	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	Alfonso Hernandez 713-520-8670
TANGO	Wednesdays 1:00—2:15 pm	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	Alfonso Hernandez 713-520-8670
 DANCE	Mondays Call for information	Houston Ballet Center for Dance 610 Preston Houston, TX 77002	Kathleen Crist, LMSW 713-626-7114
SINGING	AUG—1st Monday of month 12:00—1:00 pm	Houston Ballet Center for Dance 610 Preston Houston, TX 77002	Kathleen Crist, LMSW 713-626-7114
EXERCISE	Thursdays 9:45—10:45 am	Metropolitan Multi-Service Center 1475 West Gray Houston, TX 77019	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	Kathleen Crist, LMSW 713-626-7114
PD SUPPORT GROUP	3rd Tuesday of month 10:00—11:30 am	American Red Cross 2700 SW Freeway Houston, TX 77098	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	Alfonso Hernandez 713-520-8670
 NEWLY DIAGNOSED SUPPORT GROUP	3rd Monday of month 6:30—7:30 pm	For those who have been diagnosed with Parkinson's within the last three years	Kathleen Crist, LMSW 713-626-7114

SOUTH

SPEECH & EXERCISE	Mondays 3:30—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	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	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	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	Alfonso Hernandez 713-520-8670

SOUTHEAST			
SPEECH & EXERCISE	Tuesdays 1:30—3:00 pm	Kindred Hospital Bay Area 4801 E Sam Houston Parkway Pasadena, TX 77505	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	Alfonso Hernandez 713-520-8670
SOUTHWEST			
EXERCISE	Mondays 10:00—11:00 am	First United Methodist Church 1220 FM 1092 Missouri City, TX 77459	Alfonso Hernandez 713-520-8670
EXERCISE	Tuesdays 2:00—2:45 pm	St. Phillip's Methodist Church 5501 Beechnut (Fellowship Hall) Houston, TX 77096	Alfonso Hernandez 713-520-8670
MUSIC	Fridays 10:00—11:00 am	Space is limited. Please call to register.	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	Karen Kennemer 281-358-2282
WEST			
SPEECH & EXERCISE	Tuesdays 5:20—6:50 pm	1st United Methodist Church of Katy 5601 5th Street Room 111 Katy, TX 77493	Alfonso Hernandez 713-520-8670
NORTHEAST			
EXERCISE	Wednesdays 12:00 noon—1:00 pm	HealthSouth Rehabilitation Hospital 19002 McKay Blvd. Humble, TX 77338	Alfonso Hernandez 713-520-8670
NEW PD SUPPORT GROUP	4th Wednesday of month 6:30—7:30 pm	First United Methodist Church Humble 800 East Main—Room 220	Kathleen Crist, LMSW 713-626-7114
NORTH			
WATER EXERCISE	Mondays 12:30—1:30 pm	Reliant Rehab Hospital N Houston 117 Vision Park Blvd. Shenandoah, TX 77384	Alfonso Hernandez 713-520-8670
SPEECH	Tuesdays 1:45—2:30 pm	Reliant Rehab Hospital N Houston 117 Vision Park Blvd. Shenandoah, TX 77384	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 The Woodlands, TX 77380	Alfonso Hernandez 713-520-8670
CAREGIVER SUPPORT GROUP	1st Thursday of month 1:30—2:30 pm	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	Kathleen Crist, LMSW 713-626-7114
NORTHWEST			
TAI CHI	Fridays 11:00—12:00 noon	Tomball United Methodist Church 1603 Baker Drive (Faith Building) Tomball, TX 77375	Alfonso Hernandez 713-520-8670
TAI CHI	Wednesdays 10:00—11:00 am	John Wesley United Methodist Church 5830 Bermuda Dunes (Boy Scout Building) Houston, TX 77069	Alfonso Hernandez 713-520-8670
SPEECH	Thursdays 1:00—2:00 pm	TEAM Approach Speech Therapy Center 11240 FM 1960 W. Suite 209 Houston, TX 77065	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.	Kathleen Crist, LMSW 713-626-7114

The \$64,000 Question...

Recently, a HAPS member called our office with a challenging question. His hope was to find an answer or at least find another person who has shared his puzzling experience. His question has gone unanswered, leaving his physician scratching his head. As he searches for answers we thought it might be helpful to move his question to a larger forum. Even if this column doesn't find an answer that will resolve the issue, perhaps it will find another person who is living with the same issue and facilitate a connection between individuals.

This is the \$64,000 question from Dilbert S. in Houston...

"Mainly in the morning and evening hours I have a dull ringing in my ear followed by a sharp upward internal heat spike which affects my shoulders, neck and chest with a burning heat sensation leaving me greatly fatigued. Has anyone else experienced this? Is this related to Parkinson's?"

If you have an answer or comment on this question, please contact the HAPS office by email at info@hapsonline.org or by phone at 713-626-7114. We will pass the information along. If you have a \$64,000 question related to Parkinson's disease, contact the HAPS office.

DANCE CLASS UPDATES:

- ◆ The Woodlands ParkinSI NG and Dance for Parkinson's have been put on hold due to scheduling changes.
- ◆ The Dance for Parkinson's group located at Houston Ballet's Center for Dance will meet at a new time beginning Monday, August 22nd. Contact the HAPS office, 713-626-7114, for the new time. Check September's newsletter for changes to the ParkinSI NG schedule.

NEW PARKINSON'S GENE HAS BEEN IDENTIFIED

A team of researchers at the University Department of Neurology of the Medical University of Vienna has succeeded in identifying a gene that is mutated in individuals with Parkinson's disease. The research team leader Alexander Zimprich said, "We have taken here a meaningful step forward in Parkinson's disease research."

The newly discovered gene, known as VPS35, is the sixth one associated with Parkinson's disease and the third dominant gene. "VPS35 is one of the three genes which causes late-onset Parkinson's, at an age of about 60 years old," explains Zimprich. Another dominant Parkinson's gene had already been discovered by Zimprich's team at the MedUni Vienna in 2004: the LRRK2 gene. This dominant gene causes a form of Parkinson's disease similar to "sporadic" Parkinson's.

The origin of the present research effort was an Austrian family with seven affected members who had been under the care of the Neurology Clinic at the Linz General Hospital for many years. All protein-coding DNA regions from two affected family members were completely sequenced, aided by a sequencing technology which has only recently become available. This process is called "Next Generation" parallel sequencing.

Using this new technology, scientists were able to analyze more than 30 million DNA components in just a few days. Such a comprehensive analysis of the whole genome in such a short time would have been unthinkable just a few years ago. More than 20,000 variants of the gene were found in every one of the patients. After numerous filtration processes and various exclusion steps, there was finally only one mutation in the VPS35 gene which could be responsible for the disease in the members of this family (VPS35-Asp620Asn). The researchers estimate the proportion of all cases of Parkinson's disease caused by this gene to be 1.0 percent. Indeed, Zimprich is of the opinion that we can "analyse the metabolic pathways of Parkinson's at the molecular level better" because of this discovery. This would be of great value to researchers of this disease.

Other institutes in Austria and the Helmholtz Centre for Genetics in Germany also participated in this study under the direction of Assistant Professor Dr. Alexander Zimprich.

Sources: Medical University of Vienna, AlphaGalileo Foundation. Press release.

CONTRIBUTIONS

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SUMMER LECTURE SERIES

Bridging the communication divide: strategies and treatment options

August 24th 6:30—8:00 PM
American Red Cross Building
2700 SW Freeway
Houston, TX 77098

Save the date...

A Caregiver Conference:
Practical Aspects of Parkinson's Care

Saturday, December 10, 2011

8:30 am—2:00 pm

Houston Area Parkinson Society and Houston Parkinson's Disease Research, Education and Clinical Center (PADRECC) will present "A Caregiver Conference: Practical Aspects of Parkinson's Care."

Stay tuned for more information.

Houston Area Parkinson society

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