

# HAPS HAPPENINGS

## HOUSTON AREA PARKINSON SOCIETY

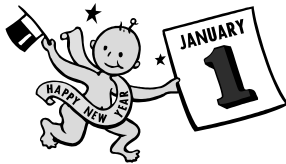
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## HOW HAPS HELPS

*HAPS serves and advocates for those impacted by Parkinson's disease in our community.*  
Houston Area Parkinson Society Mission Statement

Founded in 1974, the Houston Area Parkinson Society, a non-profit organization, is one of the oldest Parkinson's disease support groups in the United States. HAPS provides services to all counties in the greater Houston metropolitan area. Over 90% of our budget is directly devoted to our Parkinson's programs and Parkinson's research. An estimated 15,000 people in the Houston area suffer with Parkinson's devastating symptoms. As we begin this New Year, we encourage all of you to take advantage of, and benefit from, the many programs and services HAPS provides to members and non-members.

### **FREE THERAPY AND SUPPORT GROUPS**

Free therapy and support groups are available at 20 locations in the greater Houston area including: Clear Lake, Kingwood, Pasadena, Baytown, Sugar Land, Humble, Tomball, Livingston and Huffman. Programs include exercise, speech, tai chi, and water therapy groups under the supervision of licensed occupational, physical and speech therapists. HAPS also offers a support group for caregiver's who live with Parkinson's related dementia.

### **INFORMATION, REFERRAL AND SPEAKERS BUREAU**

HAPS is an outstanding resource for information concerning Parkinson's disease and its treatment for patients and families, caregivers and others affected by the disease. This includes an extensive, up-to-date lending library of books and tapes. Individual counseling on ways to cope with Parkinson's disease and Internet data searches are performed for specific needs. Referrals to various community and health care agencies are made on a case-by-case basis. Volunteers also provide information to groups in the community.

### **HOME AND RESPITE CARE**

HAPS helps relieve the stress that Parkinsonians and caregivers face with its home and respite care programs. HAPS partners with Sheltering Arms Senior Services to provide trained aides to assist with activities of daily living (bathing, dressing, feeding, toileting etc.) and to give caregivers the benefit of a few personal hours. This help is provided on a sliding scale according to household income.

# HOW HAPS HELPS *cont.*

## FREE TRANSPORTATION PROGRAM

HAPS provides free handicapped equipped van rides for those in need of transportation to the therapy sites and doctor's visits.

## EMERGENCY FINANCIAL AID

HAPS provides emergency financial aid for neurologist visits and interim medication for patients who have no personal financial resources, medical insurance, Medicare or Medicaid.

## ADVOCATES FOR THE PARKINSON COMMUNITY

HAPS volunteers work with the legislatures, government agencies and the media on behalf of those affected by PD.

## MONTHLY NEWSLETTER

Every month, the Houston Area Parkinson Society publishes HAPS Happenings. HAPS Happenings brings over 2000 people news, articles, tips and other information of interest and importance to the Parkinson's community.

## FREE ANNUAL SYMPOSIUM

Each year, during Parkinson's Awareness Month, HAPS brings in nationally recognized speakers familiar with the latest in research and treatment for a full day symposium during Parkinson's Awareness month. Additional workshops are presented during the year.

Leading scientists describe Parkinson's as the "most curable neurological disorder." Until the cure is found, the Houston Area Parkinson Society will continue to provide and expand upon the multitude of diverse services to help ease the burden for Parkinsonians and their families.

The quality of life for the participants in HAPS programs will be diminished if these services are not adequately funded and expanded. We cannot let that happen! We don't have to let that happen! **YOU CAN HELP HAPS!** Include HAPS in your New Year's resolutions.

## NEW YEAR'S RESOLUTIONS

- ⓪ **WORK FOR THE CURE!** Take an active role this year in whatever way you can participate. Educate yourself and others, write letters and make calls to policy makers.
- ⓪ **VOLUNTEER YOUR TIME!** Just give us a call. HAPS has *all kinds* of ways you can help.
- ⓪ **VOLUNTEER YOUR MONEY!** Instead of giving or receiving gifts for special occasions, make the gift more special with a donation to HAPS in honor of the occasion. And at those sadder times, remember those you cared for with a contribution in their name.
- ⓪ **PLAN YOUR GIVING!** Integrating a charitable gift into your overall financial, tax, and estate planning objectives can maximize benefits to both you and HAPS.
- ⓪ **MATCH YOUR GIFT!** Many industrial corporations and companies will match contributions given by their personnel to not-for-profit charitable organizations.
- ⓪ **DO A GOOD DEED!** Many people spend years undiagnosed because their primary care physician is unfamiliar with the symptoms of Parkinson's disease or they may be diagnosed without being aware there is more help available. Call the office and request brochures to distribute and discuss with your physicians.





# Ask Dr. Jankovic

*Joseph Jankovic, M.D. is Professor of Neurology and Director of the Parkinson's Disease Center and Movement Disorders Clinic Department of Neurology, Baylor College of Medicine*

**Q: How do we measure severity of PD and what does it mean to the overall functional impairment.**

A: Although PD is a progressive disease, not everyone progresses at the same rate. What determines the natural course of the disease and how do we measure it? Progressive decline in motor function is the expected natural course of PD, but there is little or no information on what demographic or clinical features determine or influence the rate of progression of the disease and of the different symptoms. Although some studies have attempted to address this important issue, most are flawed because of small sample size, short duration of follow up, and other methodological problems. While the variability in clinical expression of PD is well recognized, the long-term prognosis of the different clinical subtypes has not been studied prospectively. Furthermore, clinical observations have suggested that different parkinsonian features progress at different rates. We have recently published a study, based on 297 patients followed for at least 3 years at Baylor College of Medicine Parkinson's Disease Center and Movement Disorders Clinic, that attempts to address these questions [Jankovic J, Kapadia AS. Functional decline in Parkinson's disease. *Archives of Neurology* 2001;58:1611-1615].

Before discussing the results of the study it is important to describe how clinicians assess motor and mental impairment associated with PD. Although there are many computer-based instruments and techniques to measure the various signs related to PD such as tremor (shaking), slowness of movement (bradykinesia), stiffness of muscles (rigidity), and postural instability (loss of balance), most neurologists involved in PD research use a rating scale called Unified Parkinson's Disease Rating Scale (UPDRS). I recall the initial meeting in Bermuda in October 1984 when, along with other PD researchers, we were "locked" in the hotel conference room and were not allowed to go out and enjoy the beach until the scale was completed.

Published in 1987, the UPDRS, which consists of 42 items related to mental functioning, activities of daily living, various motor signs, and response to levodopa, has become the standard method of assessing symptoms and signs of PD. In the recent article, based on the analysis of 1731 consecutive visits that included UPDRS assessments over a period of an average of 6.36 years (range: 3-17), we found that in contrast to motor decline there was very little overall impairment in mental functioning. Patients with older age at onset (57 years old or older) had a more rapid progression of disease than those with younger age at onset (younger than 57 years). Furthermore, the older onset group had significantly more progression in mentation and had more freezing. Handwriting was the only component of UPDRS that did not significantly deteriorate during the observation period. Furthermore, progression was faster in patients with PD dominated by postural instability and gait difficulty (PIGD) as compared to those PD patients with the tremor as the dominant feature. These findings, based on longitudinal follow-up data, provide evidence for a variable course of progression of the different PD symptoms, thus implying different biochemical or degenerative mechanisms for the various clinical features associated with PD.

The natural history of PD appears to be influenced not only by the age at onset and the clinical presentation, but also by a number of other factors, such as stress, pregnancy, and therapy. Although therapeutic advances have had a positive impact on the quality of life, epidemiologic studies have not been able to demonstrate that levodopa significantly prolongs life. Several studies, however, have concluded that PD patients have a nearly normal life expectancy.



# STAY ACTIVE



...other New Year's Resolution)

Staying active is important in helping preserve muscle tone and function for maintaining mobility, balance and coordination, as well as an overall feeling of well-being.

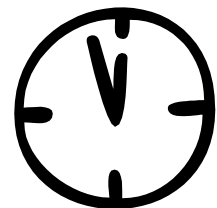
Researchers interviewed 663 people over the age of 65 in an 8-year study and found those who tended to decrease their level of physical activity as they aged tended to be more depressed regardless of socioeconomic factors and health status.

An article from the Mayo Clinic Health Letter suggests that you:

- 1 *Schedule regular activity.* Your routine doesn't need to be long and tedious, but should be consistent day to day. Overexertion once a week will only tire you.
- 1 *Use your whole body.* It may be more tempting to work on walking if that's your biggest disability, but range-of-motion exercises that work from the major muscle groups to finger and facial muscles including speech or swallowing problems are just as important. HAPS therapists that can help you with all of this...free of charge!
- 1 *Eliminate distractions.* Movement may take concentration. Ask someone to move with you, but find another time for conversation or window-shopping.
- 1 *Watch your movements.* Use a mirror or ask someone to help you. As you exercise, make sure each movement extends to your full range of motion.



**IT'S NOT TOO LATE  
TO ASK YOUR FAMILY AND FRIENDS  
TO SUPPORT HAPS WITH PLEDGES**



**AND**

**RUN FOR SOMEONE WHO CAN'T!**

HAPS was selected again this year as an official charity of the Compaq Houston Marathon. Hundreds of participants running in the marathon, half marathon and 4 miler will not only be accomplishing the physical challenges of these races, but will also be dedicating their race to helping others. More than ever before **we need your help** in "getting the word out" to anyone you or your friends might know who might walk or run the Marathon, Half Marathon or 4 Miler on January 20 in behalf of HAPS.



**LET'S SUPPORT THOSE SUPPORTING US!  
HAPS needs volunteers for the day of the race!**



For more information, pledge sheets or to volunteer  
call Patricia Tilley at 713-626-7114.

# Announcing: Young Onset Support Group

If you are under 50 and have Parkinson's, this newly started group is for you! The group decided to meet on the second Wednesday of each month at St. Luke's Methodist Church, 3471 Westheimer (at Edloe). It will be held from 7:00-8:30 pm. For more information, contact Amy Haralson at 713-402-5004.



## For Your Information...

The National Institutes of Health selected the University of Rochester's Clinical Trials Coordination Center to run the largest study ever (\$6 million, five years) of several drugs for Parkinson's disease. This was due in part to the strict requirements that the University places on their scientists. To rule out bias, their researchers are prevented from benefiting financially in any way. When a drug company funds a study, the Centers researchers retain the right to write the findings and publish the data, even if the drug failed to work. Their researchers cannot own or trade in a company whose drugs or products are being investigated, nor can they serve as paid consultants to a company involved or related to a study. They must also agree not to inform relatives or friends about the research.

Now for an eye-opener! Prestigious journals such as Nature, the Journal of the American Medical Association and the New England Journal of Medicine are now requesting scientists who submit articles about drug trials to *also* disclose any financial interests related to their studies. In addition, these journals have instituted new policies designed to support a scientist's right to publish—even if the research shows a drug has failed to work. Who would have thought that they didn't before?



## CONTRIBUTIONS

-your donation is much appreciated-

### Gifts

Houston Endowment Inc.

### Memorials

*In Memory of David O. Guillory, Jr.*

Julia & Dexter  
Ellen & Turner

*In Memory of Earnestine Goebel*

Billy & Patricia Brown  
Eloise Brown

*In Memory of Ann Oates*

Mrs. R. L. Coffman  
Mrs. Thaine Hurst

*In Memory of Willoughby Pettigrew*

Susan Hancock

*In Memory of Jaunita Fitch Rogers*

Howard & Maude Eckart

Donna & Edmund Mackert

### Memorials

*In Memory of James D. Pressly*

Polly & Jim Bob Saunders

*In Memory of Fay Rudolph*

Margaret Green  
Nancy & Bob Martone

*In Memory of Paul Storck*

Mr. & Mrs. Nolan Barth  
Mr. & Mrs. W. A. Ganske

*In Memory of Mr. & Mrs. Henry Peters*

Susan Hancock

*In Memory of William Webb Swanson*

Howard & Bobbie Naughton

*In Memory of Joseph E. Terrill*

Jerry, Louise, John & Anne Terrill

## MEET YOUR BOARD OF DIRECTORS

Let me introduce  
myself...



My name is Amy Haralson. I have been married for 18 years to Walt Haralson. We have 2 children, Holly Victoria, 15, and William John II (Jay), 10, whom we adopted from Russia in 1996. They are both very special kids and needless to say, we are so proud of them.

I am a native Houstonian, graduated from Lamar High School and went on to Texas A & M University where earned a Bachelor's degree in Chemistry. For about 20 years, I utilized that degree with the Houston Police Department and the Harris County Medical Examiner's Office as a Forensic Chemist and Crime Scene Investigator, the first woman in the City of Houston to do this.

A few months after retiring from this field, I was diagnosed with Parkinson's disease at age 41. My family doctor sent me to the best PD neurologist that he knew, Dr. Leanne Burnett. She introduced me to HAPS when she saw my "involvement" ethic. She also knew that I was researching everything that I could get my hands on about this disease. With my scientific background, she also knew that I could easily decypher the medical jargon and ask informed questions and make equally informed decisions. I am so glad that she has agreed to take the torch for HAPS that Bob held so well for so long.

I am now a full-time Methodist minister and am going to graduate school in Theology pursuing ordination as an Elder in the United Methodist Church. My goal is to actually walk to the front to be ordained in several years. With Leanne as my partner, how can I miss?

I am Corresponding Secretary and currently working with Anne Martin on a Young Onset support group.

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