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HAPS HAPPENINGS

APRIL 2007

2700 SOUTHWEST FRWY. #284

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Polish-up on Parkinson's

HAPS Annual Symposium Saturday, April 21, 2007

The United Way Building
50 Waugh Drive
Houston, TX 77007

Schedule of Events:

- 8:30 AM:** Doors open
Continental Breakfast and Community Resource Exhibits
- 8:55 AM:** Welcome
- 9:00 AM:** Non-Motor Symptoms of PD
Dr. Eugene Lai
- 9:45 AM:** Break
- 10:00 AM:** PD Rx and Over-the-Counter Meds
Jeff Sherer, Pharm.D.
- 11:00 AM:** Lunch
- 11:45 AM:** Mental Health Issues and Treatment
Dr. Christopher Kenney
- 12:45 PM:** Break
- 1:00 PM:** Ask the Neurologist/Neurosurgeon
Dr. Mya Schiess and Dr. Richard Simpson

Transportation available from outlying areas.

RSVP by Wednesday, April 19, 2007

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April is Parkinson's Awareness Month

Nina Brown

Living with Parkinson's disease is a lot easier if your family and friends, the general public and health care professionals (in hospital situations, assisted living, nursing homes) understand and are aware of the complexity of the disease. There are many idiosyncrasies associated with Parkinson's disease that are rarely mentioned in textbooks. Since April is Parkinson's Awareness Month, why not share this information to help others understand...they *need* to know.

☞ **Make them aware** that your difficulty in moving may result from slowness (bradykinesia), rigidity, poor coordination, weakness in your arms or legs, poor posture, and/or problems with balance and falling. Your gait may, or may not, be hampered from a shortened stride, dragging your toes, shuffling, freezing or by taking short quick steps (festination).

☞ **Make them aware** that your ability to function is determined by the timing and effectiveness of your medication and can change, not only by the day, but also by the hour. Fluctuations, such as involuntary movements (dyskinesia) or drug-induced tremor, may occur when the medication is at its peak dosage. At the end of a dose, you may experience cramping (dystonia), lethargy, a period where it's "wearing off," or have an "on-off" response. When medications are not given on a precise schedule, the side effects can affect your entire state of well-being. Therefore, it's particularly important that you make sure that health professionals understand the problem because *their* pattern of dispensing medication may not necessarily match *your* needs.

☞ **Make them aware** it takes a cooperative effort to time your medication dosage. Parkinson's is not a disorder where everyone gets the maximum results with the usual "take three times a day with meals" instructions. Because of disease progression, continuous monitoring and medication adjustments are required to accommodate the body's changing needs.

☞ **Make them aware** that you may be taking additional drugs for other problems and care must be taken to avoid any interactions.

☞ **Make them aware** that an unexpressive face is a symptom of Parkinson's; it is not a sign of disinterest or a lack of understanding. Help them understand that it is the rigidity from Parkinson's that creates the blank expression and can also affect your eye control and blinking reflexes. Explain that some people develop a weak voice with rapid, slurred speech and may drool because of internal regulatory problems. Request that people speak directly to you even if it takes a little longer for you to put the words together for a reply.

☞ **Make them aware** some people have tremors and others do not. Some may have urinary incontinence or retention, constipation problems or sweat excessively. Some do not.

☞ **Make them aware** that some people are able to eat without a problem, while others have trouble swallowing and chewing.

☞ **Make them aware** some people with Parkinson's become depressed, have memory problems, are unable to pay attention, or may hallucinate. Health care workers should be aware that episodes of dementia or hallucinations could be caused by a medication overdose or interaction.

☞ **Make them aware** your sleep may be disturbed and possibly affect your functioning during the day.

☞ **Make them aware** that any kind of stress increases symptoms in direct proportion to the stress.

The signs and symptoms are numerous and variable between individuals so you are the only one who really knows what it's like *for you* to live with Parkinson's; but your life may be easier if you make others aware.



Medical Advisory Committee Announced

The Houston Area Parkinson Society is honored to announce that the following distinguished professionals have so generously agreed to serve on the 2007 HAPS Medical Advisory Committee. HAPS thanks them for their commitment and enthusiasm.

Richard K. Simpson Jr., M.D., Ph.D., F.A.C.S.- Committee Chairperson

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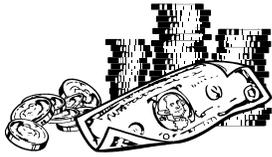
New Low-Cost Diagnostic Test for Parkinson's

Currently there is no specific diagnostic test for Parkinson's disease. Doctors rely on their observations to make a diagnosis, which means some patients may not be prescribed the most suitable medication and around 15% of those diagnosed may actually be suffering from something else.

Now, scientists in Australia have developed a cost-effective gene-sequencing chip that will allow for routine testing of people suspected of having Parkinson's disease. It will also assist researchers in understanding the genetic basis of Parkinson's and allow large-scale studies that could identify more genes that cause this debilitating condition.

In addition to providing a genetic diagnosis, it is hoped that the chip will eventually be able to pinpoint genetic changes that help to predict a person's prognosis and even the treatment that best suits them.

Since the test is relatively cheap and only involves collecting a sample of blood or saliva, it could also be made available to the patient's relatives and those at risk of developing Parkinson's. More genetic information will deepen our understanding of Parkinson's and enable researchers to work toward prevention and treatment.



The Cost of Parkinson's Disease



Putting aside the emotional and physical cost of living with Parkinson's, tax season forces us to add up the financial burden as well

Using a database of insurance-claims information from 10,445 people with Parkinson's (average age, 72.7 years and 43.5%, female) who had either had two visits with a physician for the treatment of Parkinson's or one visit for treatment and two prescriptions for drugs to treat Parkinson's over an average of 675 days, researchers found that their annual health care with private medical insurance was \$16,634 per person compared to those on Medicare which was \$6,711 per person.

It has been estimated that 31% of those who are employed with Parkinson's will lose employment within a year. Disability subsidies can run \$30,000 or more annually.

In 1997, researchers estimated that the annual economic burden associated with Parkinson's disease in the United States was \$25 billion.

- ⑤ In the typical early stage of the disease, annual medical care per person costs \$2,000-\$7,000 per year, which rises as the disease progresses.
- ⑤ L-dopa and related drugs run \$1,000 - \$6,000 per year.
- ⑤ With an estimated 38% of Parkinson's patients who fall (13% more than once per week) treatment and hospitalization for Parkinson's-related falls can run \$40,000 per year or more per person.
- ⑤ Assisted Living and Nursing Home care can exceed \$100,000 per year per patient.

We spend more than \$1 trillion on health care each year in this country, of which three-quarters - \$750 billion - goes to chronic diseases.

When you consider the costs involved, wouldn't the country come out ahead by spending more money for research to find a cure? Another reason to make your voices heard.



You Have to Laugh



- ☹ The only thing that hurts more than having to pay income tax is *not* having to pay income tax.
- ☹ The U.S.A. is the only country where it takes more brains to fill out the income tax forms than it does to make the income.
- ☹ There will always be death and taxes; however, death doesn't get worse every year.
- ☹ A fine is a tax for doing wrong. A tax is a fine for doing well.

CONTRIBUTIONS

Your donation is much appreciated. Your thoughtfulness helps HAPS continue to provide much needed services to people with Parkinson's and their families.

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Shirley & Jay Marks

In Honor of Ned Smith

Ellen Smith

In Honor of George A Bourgeois, III

George & Sherry Bourgeois

IN MEMORY OF

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HAPS HAPPENINGS is published monthly by the Houston Area Parkinson Society Editor: Nina P. Brown



The mission of the Houston Area Parkinson Society is to improve the quality of life for those affected by Parkinson's disease through services, education and advocacy.

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