

JANUARY 2013

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Letter from the President



Dear Friends,

Looking back on the past year, Houston Area Parkinson Society has made great strides in advancing its mission. On a daily basis, HAPS provided valuable services and programs throughout eight counties that improved the quality of life for those affected by Parkinson's. It supported numerous families through the progression of the disease, educating them and giving them the necessary tools for managing this varied and complex movement disorder. HAPS contributed to the greater Parkinson's community raising awareness of the disease by putting a face on Parkinson's through those living with the diagnosis, while advocating for a cure.

As we continued important ongoing partnerships and initiated new ones, HAPS expanded its services to meet the needs of the community offering client-centered, innovative programs that address the intricacies of Parkinson's disease. Although there are other organizations in the area that offer certain programs for individuals with Parkinson's, HAPS distinguishes itself as the only PD patient support organization in metropolitan Houston that makes free comprehensive services available which include:

- **Thirty-four weekly therapeutic exercise groups led by professionals throughout the Houston area**
- **Nine support groups led by licensed Master's level social workers who also provide information, referral and a full range of social services**
- **Subsidized funding for respite care for those in need who qualify**
- **Transportation to HAPS exercise groups and doctor's appointments**
- **Emergency financial aid for Parkinson-related medical appointments, medications, medical equipment and essential basic needs**
- **Information resources, a monthly newsletter and website with the latest information about Parkinson's research and treatment**
- **Workshops, lectures, educational programs and annual symposiums**

We look ahead to our 39th year as a strong independent organization with great optimism, passion for the cause and vision for the future. HAPS will proudly welcome six exceptional new Board members at its Annual Meeting this month. In March, the Board of Directors will engage in critical dialogue and establish significant goals for the organization at the Ted Gilbreath Biennial Strategic Planning Session.

HAPS will represent Houston's Parkinson community nationally at the Parkinson's Action Network conference in Washington, D.C and internationally as an Organizational Partner of the 3rd World Parkinson Conference in Montréal, Canada this year opening doors for worldwide discussions on crucial issues facing those affected by Parkinson's.

With the outstanding commitment of the many foundations, corporations and individuals who make our efforts possible, we are able to fulfill our mission. We remain grateful to the members of the HAPS family for the enduring support they provide and the tremendous meaning they bring to all that we do.

HAPS offices and groups will be closed Monday, January 21st for Martin Luther King, Jr. Day.

**PAN Forum
2013
Washington, DC
Feb 25-27**



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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Welcome New HAPS Board Members!



JOYCE GILBREATH is a native Houstonian who received a BBA with a major in Marketing from The University of Houston in 1968. After taking time off to raise a family, Joyce later changed careers and entered nursing school at The University of Texas Health Science Center and earned a Bachelor of Science in Nursing in 1987. She worked at M. D. Anderson Hospital as an R.N. and Research Nurse in the Leukemia Service for 10 years, before retiring in 1997. Since retirement, Joyce has been involved with several volunteer organizations and travels annually to villages in Guatemala to provide health services with *Faith in Practice*. For the past 10 years, she has been involved with HAPS along with her late husband and former HAPS Board Member, Ted.



JIM NICKLOS has been the President of Nicklos Drilling Company since 1997, with a longtime career in the oil, gas and drilling industry. He received his Bachelor of Science from University of Colorado, Boulder in 1971 and went on to become CEO and President of Nicklos Oil and Gas Company/Nicklos Drilling Company through 1986. Since then, he has founded, developed and sold various drilling companies. In addition to his career achievements, Jim currently serves on the Houston Ballet Foundation Board of Trustees as Chairman of Finance and has been a Stages Repertory Theatre Board Member for over a decade where he previously served as President and Chairman of Finance.



MARK OHLS is a Residential Mortgage Banker of twenty-two years, currently employed by Houston Capital Mortgage. He was born and raised in Houston and graduated from University of Texas in 1978. Mark is a member of The Church of St. John the Divine Episcopal where he serves as a member of the Associate Vestry and is also a member of the Finance Committee of Christian Community Services Center. Mark has previously volunteered at Texas Children's Hospital, The Beacon of Christ Church Cathedral's Health and Outreach Ministries, American Heart Association and American Cancer Society. He is married to wife Carla Neff Ohls and the two are parents of twenty-four year old twins, Laura and Harrison.



TERRY K. SATTERWHITE, M.D. is the former J. Ralph Meadows Professor of Internal Medicine at The University of Texas Health Science Center at Houston. He attended medical school at Bowman Gray School of Medicine, Wake Forest University and post graduate training in internal medicine and infectious diseases at Emory University and Vanderbilt University. He joined the faculty at The University of Texas Medical School at Houston in 1974 serving as Medical Director at Hermann Hospital. Terry received numerous honors, including the Distinguished Physician Award from Hermann Hospital and the Benjy F. Brooks, M.D. Outstanding Clinical Faculty Award from The University of Texas Medical School at Houston Alumni Association. He is Professor Emeritus at The University of Texas Medical School at Houston.



RANDI SMITH has been an active volunteer for multiple non-profit groups benefitting Parkinson's Disease since her father was diagnosed just over 12 years ago. In June 2012, Randi launched her neckwear line, B.Necil, which includes ties, bowties and pocket squares, with each design supporting a particular cause, one of which is Parkinson's disease. Outside of Randi's involvement with several other non-profit organizations, Randi serves as Vice President of Leasing at PM Realty Group. Prior to joining PMRG, she spent two years at Grubbs & Ellis Company where she earned the 2006 Rookie of the Year award. Randi is also an active jazz vocalist performing in the greater Houston area.



MICHAEL YOUNG is Director of Corporate Real Estate, Facilities, and Records Information Management for Houston-based independent power producer, Calpine Corporation. Originally from the Midwest, Michael moved to Texas over three decades ago. Outside of his devoted work ethic, he enjoys spending his leisure time in the company of his friends, family and dog, Atticus. Michael has been an avid supporter of HAPS since he ran the Chevron Houston Marathon for HAPS in 2008 in honor of his close friend, Doug Benzuly, raising over \$8,000. He continued his support of the organization by helping Doug launch the annual fundraiser, "Playing for Parkinson's," which benefits HAPS.



Play a Part in Parkinson's Research

Update on The Parkinson's Progression Markers Initiative

The Parkinson Disease Center and Movement Disorder Clinic at Baylor College of Medicine is a clinical site for the Parkinson's Progression Markers Initiative (PPMI), the first-ever large-scale study exclusively focused on identifying and validating Parkinson's disease biomarkers. Biomarkers are critical to accelerating the development of disease-modifying therapies that can transform patients' lives.

A biomarker is a substance, process or characteristic in our bodies that is associated with the risk or presence of a disease, or that changes over time in a way that can be linked to the progression of a disease. Reliable and consistent biomarkers allow scientists to predict, objectively diagnose and monitor diseases as well as definitively determine which medications work and which do not. There is no currently known biomarker for the progression of Parkinson's.

Currently, Parkinson's patients only have treatments that temporarily alleviate symptoms. If a biomarker is found through PPMI, researchers will have a critical tool to aid the quest for disease-modifying therapies that can slow or stop the progression of the disease.

PPMI Is Making Progress

Since its inception two years ago, PPMI is making progress. The study is being conducted at 24 sites across the United States, Europe, and Australia, and has recruited more than three-quarters of the needed 600 PD and control participants.

In addition, the scientific community at large now has access to the largest repository of PD data and biological samples collected to date. Researchers are taking advantage, and have already begun to analyze biological processes taking place in PD that could lead to verified biomarkers. PPMI data has been downloaded more than 35,000 times by over 200 scientists across 28 countries worldwide; 1,500 biospecimens are also now available for laboratory study.

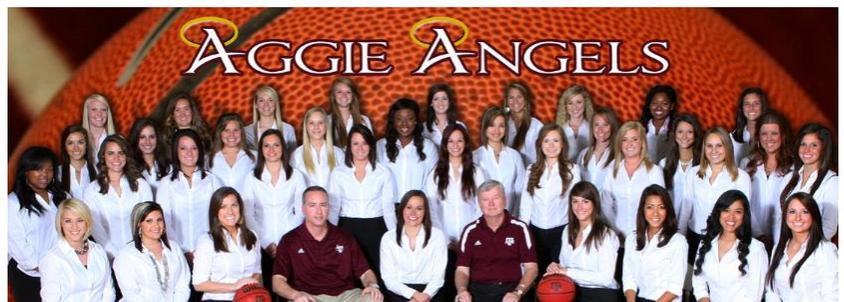
Of course, PPMI is still in its early stages—many study participants have only completed the first few months of the study, which will last up to five years. As more follow-up visits take place, scientists will be better able to refine their analyses through comparative analyses of longitudinal data (data taken at specific intervals over a period of time).

There is still work to be done to fully recruit PPMI, an important step in ensuring the study's success. Specifically, the study seeks people who have been diagnosed with Parkinson's but who have not yet started taking medication. Also, men without Parkinson's over the age of 55 and women without Parkinson's over the age of 65 are also needed to serve as controls. Participants' health will be closely monitored by experienced doctors and nurses. They will be compensated for travel and time in the study, and their privacy will be closely guarded. Most importantly, they will have the personal satisfaction of being part of a study that could help speed a cure for Parkinson's disease.

Visit www.michaeljfox.org/PPMI to learn more about the study. For information about PPMI at Baylor, contact Christine Hunter at 713-798-3951. If you don't qualify for PPMI, you can still help spread the word to people who might be interested in participating.

Aggie Angels Team Up with HAPS in Marathon to Raise Awareness of Parkinson's

Aggie Angels is the hostess group for Men's and Women's Basketball at Texas A&M. They promote and attend all basketball games in the Bryan/College Station area as well as participate in many local philanthropic events. HAPS was an easy choice for the *Angels* after Texas A&M head basketball coach, Bill Kennedy, was diagnosed with early-stage Parkinson's disease in 2011. Inspired by Coach Kennedy, the *Angels* decided to give back to the community by raising money, educating college students about PD and showing support for the Aggie Athletic family. This year, four members of the *Aggie Angels* will be running the half marathon on January 13th, along with 38 others cheering from the



side lines as they fundraise for HAPS and awareness of Parkinson's. You can support the Aggie Angels or any Marathon fundraiser now through February 15th by going to www.hapsonline.org and clicking the marathon donation button. Thank you Angels!

The Big Picture: Studying Populations to Understand Parkinson's

By Beate Ritz, MD, PhD



Despite the significant progress we have made in diagnosing and treating Parkinson's disease (PD), many basic questions remain unanswered.

Among them: How many people have Parkinson's disease? What puts people at risk of developing PD? Are there some groups — for example, people who live in certain geographic locations, or are of particular ethnic backgrounds — who are more likely than others to develop PD? Are people being diagnosed with Parkinson's more frequently than before? Are there toxins in the environment, or aspects of people's lifestyle, that contribute to PD? And the elusive "holy grail," is there anything that could prevent it?

Epidemiologists approach these problems by studying large groups of people over long periods of time. They use these data to formulate a picture of who gets certain health conditions, and to investigate whether chemicals, or foods and health habits, among other things, might cause disease or protect against it. The answers they receive can help us to understand, treat and — in the long run — prevent many health conditions, including Parkinson's disease.

Getting at PD Risk and Protective Factors

Through epidemiological studies of this kind, we do already have some basic information about how many people live with Parkinson's, and who has a higher risk of developing it.

For example, in the United States, studies have shown that in the population aged 60 years or more, about one percent — or five to 10 adults per thousand — have Parkinson's. That makes PD the second most common neurodegenerative disease after Alzheimer's.

We know some other things about people who are more or less likely to develop Parkinson's disease. These factors include the following:

- Age is the chief risk factor for Parkinson's. As the number of people over age 60 increases, an increasing number of people will be diagnosed with PD.
- PD is more common in men. About 60 percent of people with PD are male and 40 percent are female.
- PD is more common among whites than it is among blacks, or among people of Asian ancestry.
- People who have Parkinson's report that they smoke less and drink less coffee than do other people. But we

do not know whether long-term use of caffeine or nicotine may prevent PD or whether people with PD may simply stop drinking coffee or smoking in the early (or preclinical) phase of PD. Or could it be that these behaviors are part of what some doctors hypothesize to be "a Parkinson's personality?"

Research has suggested other factors that may reduce PD risk, although these are not proven. They include taking anti-inflammatory medications and statins; exhibiting high blood levels of uric acid; and eating foods rich in antioxidants, or taking supplements. Research also suggests factors that may increase the risk of developing PD, including living in a rural area, working as a farmer, and drinking well water. Stronger evidence points to occupational and general exposure to pesticides, and perhaps exposure to certain metals and to PCBs (organic chemicals), as increasing the risk of PD.

We discovered these associations by looking at behavioral and health data, from thousands of people, that originally had been collected over many decades for another purpose altogether. In one example of this type of research, researchers set about gathering health information regularly on more than 8,000 men of Japanese ancestry who lived in Hawaii in 1964, with the purpose of studying heart disease. But the scientists also followed these men for other aspects of health, including Parkinson's diagnoses. In the 1990s, looking back at almost 30 years of records, researchers compared the 149 men who had developed PD with others in the group. They found that the men who were smokers or who consumed caffeine at the beginning of the study were less likely to have developed PD than were the others. Later studies bolstered these observations.

It is important to remember that these risk factors, generally do not necessarily cause Parkinson's disease. But they can help us understand how it develops. Knowing the agents that may be harmful to dopamine neurons may help us find ways to reduce our exposure to them. It can help us to better understand how toxins may increase the risk of developing PD, and thereby help us to identify new targets for treatments.

The Importance of Disease Registries

So far, epidemiologists interested in PD have had to rely mainly on large long-term studies that were designed to study other illnesses. Why are there so few studies and databases designed for Parkinson's?

One reason is that in the United States, there is no centralized place for recording cases of Parkinson's as

there are for many other diseases. A second reason is that gathering information about cases of PD is more difficult than for many other diseases. For example, if you want to find out the ages at which people die from strokes, you can look at death certificates. If you want to see who has cancer, the diagnoses will be confirmed by pathologists' reports. But PD often is not listed on death certificates and PD diagnoses are not always accurate. Unless a person with PD has been diagnosed by an experienced movement disorder specialist, there's a strong chance of PD being confused with diseases such as Multiple system atrophy (MSA), Progressive supranuclear palsy (PSP), or Essential Tremor.

In countries with national health care, it is theoretically easier to assess the prevalence of PD. But even here there are problems — for example, numbers cannot be easily compared country-to-country because different methods have been used to identify PD. Even in a small country like Norway, which has universal health care, centralized record-keeping and well-trained physicians, a recent study showed that tremor disorders were often misdiagnosed as PD by non-specialists.

To truly understand PD, we need a focused approach — ideally, a disease registry that includes confidential information on health and other characteristics (for example, employment and residence) for everyone with PD who lives in a large county, state or country.

California Parkinson's Disease Registry

In 2004, in an effort to begin gathering data on PD in a well-defined US population, I worked with a group of collaborators — including Greg and Ann Wasson, Mark Siegel, and Drs. Caroline Tanner and J. William Langston — to pass a law establishing the California Parkinson's Disease Registry. The law mandates the Department of Health to register cases of PD in a confidential database, and it requires health care providers to report cases to the registry. But it too has faced challenges — a key one being that the law forbids the expenditure of state funds to run the registry itself!

In 2007, with many colleagues, I began a pilot project to develop this registry. We focused on three counties in California's Central Valley, which is the nation's most productive agricultural region. We chose this area in part because we wanted to investigate a suspected association between pesticide exposure and PD. It took months of legwork to contact health care facilities and physicians treating people with PD; to encourage their participation; and then to recruit people in the registry to participate in our research.

Following up on mounting evidence that pesticide exposure increases PD risk, one of our first projects with the registry was to look at people who live close to fields

that had been sprayed with the fungicide maneb and the herbicide paraquat. We found that these people had an increased risk of developing PD. In a later study, we found that people whose workplaces were near fields sprayed with these pesticides, as well as the fungicide ziram, had an increased PD risk. People who both lived and worked near fields sprayed with pesticides had the highest PD risk. People who were diagnosed with PD at younger ages had higher exposures to pesticides — both at workplaces and at home.

In another project, we followed 233 people recently diagnosed with PD for five years, to investigate why it is that some people with Parkinson's live for many years without much change in their movement symptoms, whereas others decline rapidly. This long-term study allowed us to compare the genes of "fast progressors" and "slow progressors." One important result of the study was the identification of genetic variations that may help predict the course of a person's PD and suggest a way in which we can identify people with PD who will benefit the most from early treatment.

In a fairly short time, with a PD registry representing only part of our state, we have already accumulated strong scientific evidence both to support changes in environmental regulations and to suggest pathways to developing neuroprotective agents (that is, agents that can protect neurons from dying in PD). These results underscore the need for more comprehensive PD registries in California and elsewhere.

What You Can Do

If you are a person with PD, you can make a contribution to research by contacting a PD registry, if there is one near you. If you live in the majority of states that don't have registries, you can volunteer for studies and encourage people without PD to do the same. The biggest impediment to observational studies is recruiting volunteers who don't have PD. We need to include their survey responses and DNA samples, so that we can compare their histories to those of people with PD and find the differences.

Studying populations makes it possible to get at some of the most fundamental questions of research — the who, when and why of Parkinson's — and you can be a part of this process. We cannot do it without you!

This article was originally published in the Winter 2013 edition of the Parkinson's Disease Foundation (PDF) quarterly newsletter, News & Review. It is reprinted, in its entirety, with permission from PDF. For other publications, please visit www.pdf.org.

Texas does not have a PD registry, but you can contact Parkinson's Disease Foundation at www.pdf.org to learn more about existing registries or www.parkinsonsaction.org for information about the National Neurological Diseases Surveillance System Act under consideration by Congress.

CHANGING the face of PARKINSON'S

In the December edition of HAPS Happenings, we discovered after going to print that a section of the list of supporters was inadvertently left out. We sincerely apologize for this oversight and are republishing the list in its entirety as we again thank all of those whose support made the 2012 Annual Awards Event such a huge success.

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The PAN Forum is a three-day conference held in Washington, D.C., bringing together Parkinson's advocates from across the nation. Attendees gather to learn the latest in public policy and research in Parkinson's disease. Working together, Forum attendees increase awareness of Parkinson's and learn to advocate for better treatments and a cure.

The 2013 Forum will feature:

- panel discussions about **telemedicine**, the **drug development pipeline**, and **exciting new research** in Parkinson's disease;
- a panel allowing attendees to learn more about **the national Parkinson's disease organizations**;
- **Christopher P. Austin, M.D.**, director of the newly formed National Center for Advancing Translational Sciences at the National Institutes of Health;
- **Davis Phinney**, former professional cyclist and person living with Parkinson's;
- and the 2013 **Postdoctoral Investigator Poster Session** and Samuelson Reception.

For more information about the PAN Forum or if you want to register to attend go to www.panforum.org or call 1-800-850-4726.

CONTRIBUTIONS

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