HOUSTON AREA PARKINSON SOCIETY

HAPS HAPPENINGS

Celebrating 40 Years of Serving the Community 1974-2014

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APRIL 2014

IN THIS ISSUE

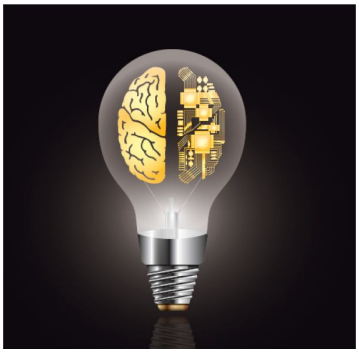
April 11th is Parkinson's Awareness Day in honor of Dr. James Parkinson's birthday!

Parkinson's Awareness Month!

April has officially been designated as Parkinson's Awareness Month. It is during this time each year that we are especially united in our global mission to raise awareness of what life is like for the nearly 7-10 million people worldwide who have been diagnosed with Parkinson's disease. We come together not only to reach out to family, friends and the general public to help them better understand what it mean to live with the chronic, progressive nature of Parkinson's, but to continue to advocate for ongoing support of research aimed at advancing treatment, improving quality of life and finding a cure.

It is equally important during this month that we remain aware of how much people with Parkinson's and their family members accomplish each day despite living with this neurodegenerative disease. HAPS is especially inspired by all of the members who show up day after day to participate in our programs—it is their involvement and contributions that keep HAPS services so relevant and of value to the community.

Parkinson's Awareness Month is about education, advocacy, support and understanding, but it is also about empowerment, appreciation, dedication and hope. Get started this month and join HAPS in spreading the word about Parkinson's disease. Get involved in the many activities being held around the local community, the country and the world as we work together to raise global consciousness of Parkinson's. Wear a Parkinson's or HAPS t-shirt; attend a webinar or conference on Parkinson's; write a letter to the editor of the newspaper or to your congressional leader; participate in the Parkinson's Unity Walk in NYC on Saturday, April 26th; attend an exercise or support group; or just tell your story to someone else. Together we can make every month Parkinson's Awareness Month!



Innovations in Parkinson's Disease:

Past, Present & Future

2014 HAPS Annual Educational Symposium

Saturday, May 10, 2014
8:30 am—3:30 pm

United Way
50 Waugh Drive Houston, TX 77007

Registration opens April 10th
Be the 40th person to register and win!

See brochure insert for more information about this year's symposium.

Novel Formulation of Levodopa May Ease Parkinson's Symptoms with Fewer Pills

People with Parkinson's disease (PD) who took a new formulation of levodopa tablets three times a day had more constant levels of the drug in their systems than those who took standard immediate-release levodopa four or five times a day, according to a new study in the journal *Movement Disorders*. The study also found that the new drug worked equally as well as optimized doses of levodopa.

Levodopa remains the gold-standard drug used to treat the motor symptoms of Parkinson's disease. When Parkinson's advances, people may need to take levodopa four or more times a day to control PD symptoms. Even with so many doses, the levels of levodopa in the system can drop, causing a worsening of motor symptoms as the drug "wears off."

Recently, scientists developed a novel form of sustained-release levodopa, which they hope may reduce fluctuations in levodopa levels. Compared with standard levodopa, the new form called XP21279 is absorbed throughout the intestines (instead of only in the upper part of the small intestines) and is a "slow release" formulation, meaning it is absorbed into the body from the intestines over a longer period of time instead of all at once. This means it could be taken only three times daily instead of four or more.

Researchers led by Peter LeWitt, M.D., at Henry Ford Hospital and Wayne State University School of Medicine, in Michigan, compared effects of XP21279 with those of standard immediate-release levodopa. In this double-blinded study, 28 people with mid-stage PD were randomly selected to receive one of the drugs for two weeks: either XP21279 three times a day or immediate release levodopa four or five times a day. Then, each person switched groups and received the other drug/dose for two weeks.

At the end of each two-week period, Dr. LeWitt and his colleagues compared the average "off time" for each group with off times at the beginning of the study (baseline). They also examined how levels of the drugs in the blood fluctuated throughout the day.

Results

- Participants reported that off time was cut in half just by improving the way they took standard levodopa (adjusting timing and dosages).
- When participants took the new formulation of levodopa, they experienced a very similar reduction in off time as with optimized standard levodopa, but were able to achieve this taking fewer doses.
- In both groups, blood levels of levodopa were much more consistent throughout the day with the newer formulation of levodopa.

What Does It Mean?

Levodopa treatment is still the gold-standard treatment for PD. However, over time, people with PD who take the drug may experience off times, which can be very frustrating. Therefore, scientists are actively searching for new forms of levodopa or other drugs that can reduce off time. Evidence suggests that stabilizing the levels of levodopa in a person's blood could be one way of doing so.

Compared with standard release levodopa, XP21279 did provide more continuous levels of levodopa in the bloodstream. Contrary to the researchers' expectations, however, this did not result in significantly reduced off times. This may be because four people in the study failed to follow the directions about taking their medication with food, and subsequently had very poor results. Because the study is small, such problems can have large effects on the data. Thus, more research will be needed to establish whether or not the new drug can actually help reduce off times. Nevertheless, this experimental drug was able to achieve similar effectiveness as standard, immediate-release levodopa.

In the meantime, this study does suggest that XP21279 may be an additional useful tool to the arsenal of medications that may reduce off time. However, XP21279 is still in the experimental stages and it must be studied further before it can be approved by the US Food and Drug Administration (FDA) for the treatment of PD.

An interesting result of this study was that almost all the participants, who had PD for an average of almost nine years, saw great benefit simply by having their medications optimized (e.g., dosages and timing improved). This means that before the study, many participants were undertreated and may have benefitted during the trial, from seeing experts in the field of Parkinson's, called movement disorder specialists.

This article was originally published as part of "Parkinson's Science News: What Does it Mean?" on the Parkinson's Disease Foundation (PDF) website on March 20, 2014. It is reprinted, in its entirety, with permission from PDF. For other science news, please visit www.pdf.org/science_news.

April 5th Clinical Trials Fair Event—POSTPONED

FOX TRIAL FINDER
THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

Those who registered for this fair should have received a notification from The Michael J. Fox Foundation announcing that the event has been postponed as a result of some last minute scheduling conflicts at the local research sites. It is important to have all Houston area trial sites represented at the event and we plan to reschedule in the coming months when all can participate. Stay tuned for more details—we will be sure to let you know when a new date has been identified. In the meantime, you can stay up-to-date on the trials in your area that need volunteers like you by logging on to Fox Trial Finder-www.foxtrialfinder.org or email any questions to trialsfair@michaeljfox.org.

Can your health and wellbeing improve by joining a HAPS yoga or tai chi class?

According to Harvard Health Publications and information from University of Maryland Medical Center, tai chi and yoga have both been credited as effective treatments that can improve symptoms associated with arthritis, high blood pressure, pain, depression and Parkinson's disease. In the Houston area there are many Parkinson's specific tai chi and yoga classes to choose from. These programs have been modified to meet the needs of individuals with Parkinson's while remaining challenging and beneficial.

The tai chi class formerly affiliated with Parkinson Foundation of Harris County has been on hold, but HAPS is ready to resume if enough people are interested in attending. If you live in the Beltway 8/Richmond Avenue area and would like to participate in a tai chi class on Mondays from 11:00 am-12:00 pm at the Tracy Gee Community Center, contact Alfonso Hernandez at 713-520-8670 or hernandez@hapsonline.org.

For more information on other tai chi or yoga classes, check the group schedule and join a group near you!

HAPS is currently enrolling for the remaining spots available in the upcoming PEP series. Beginning April 25th, these four-hour sessions will meet at Memorial Drive Lutheran Church each Friday for five weeks and will include components of exercise, recreation, socialization, education and peer support with input from participants on content. Each five-week PEP series will enroll no more than twelve individuals to participate with mild to moderate Parkinson's who can function independently.

Registration is required—reserve your spot today by contacting Celeste Harris, LMSW at harris@hapsonline.org or 713-898-7586. If you can't attend this series, but are interested in future sessions, call to sign up for the next two beginning in August and October.

HAPS Welcomes New Director of Development

Please join us in welcoming Midge Claiborne to the HAPS staff. Midge's motivation for serving others began after she earned her Bachelor of Arts degree in English from Louisiana Tech and started her career teaching high school English. She spent 20 years in residential real estate, while also serving in various fundraising roles on the boards of several organizations. Midge's commitment to volunteerism transitioned from part-time passion to a full-time career eight years ago when she became a development professional. Having achieved great success in educational and performing arts fundraising, Midge is thrilled to be entering the world of social services fundraising, and joined HAPS March 1st as the new Director of Development. On a personal note, Midge lost her beloved Aunt Bettie to Parkinson's disease only a couple of years ago, and she is eager to make an impact to such a worthy cause. Welcome aboard, Midge!

Parkinson's in the News

Parkinson's Awareness Month is off to a great start with many newsworthy reports hitting the media. HAPS is pleased to see all of the promising Parkinson's disease research and advocacy efforts getting so much attention. Here are just a few examples of recent articles describing this progress.

Parkinson's Disease Organizations Applaud Efforts to Bring More Drugs to Market, Urge Focus be on Medications that Slow Progression of Disease

New report by PhRMA outlines potential advances in drug therapies for people with Parkinson's disease

The organizations representing the Parkinson's disease community applaud biopharmaceutical research companies for developing 37 new Parkinson's disease drugs, but call for more research to find effective medications that would target the disease directly.

In a report released March 24, 2014, by Pharmaceutical Research and Manufacturers of America (PhRMA), 37 new drugs are described as in the pipeline to help people suffering from Parkinson's disease, a chronic, progressive neurological disease affecting up to 1.5 million Americans. Parkinson's disease is a movement disorder and is the result of the loss of dopamine-producing brain cells. Dopamine, a neurochemical that controls communication between brain cells, is crucial to control of motor function. Motor symptoms may include tremor or trembling, rigidity or stiffness, bradykinesia, postural instability, or impaired balance and coordination. The broad array of non-motor symptoms includes cognitive changes, mood disorders, and sleep disturbance, among others.

Currently there is no cure, therapy, or drug to slow or halt the progression of Parkinson's disease. While medication masks some symptoms for a limited period, generally four-to-eight years, dose-limiting side-effects do occur after time. Eventually the medications lose their effectiveness, leaving the person unable to move, speak, or swallow.

"We are pleased to see that there are 37 new drugs making their way to patients," said Amy Comstock Rick, CEO of the Parkinson's Action Network. "However, the number of new drugs is not as important as whether these medications are ultimately effective in improving the quality of life for people with Parkinson's. As a community, we will continue to fight to ensure that researchers have the funds and resources they need to bring us closer to drugs or therapies that directly slow or halt the progression of this disease."

The news that these new drugs are in the pipeline is a sign that the research community is moving in the right direction to find better treatments for Parkinson's disease. In fact, some of the 37 medications in development are disease-modifying therapies that could potentially halt the progression of Parkinson's. For example, one of the medications targets a receptor in the brain that plays a major role in motor control.

All 37 drugs outlined in the PhRMA report were developed by United States-based companies conducting trials in the U.S. and abroad, PhRMA-member companies conducting trials in the U.S. and abroad, and foreign companies conducting clinical trials in the United States. The medicines are either in clinical trials or awaiting review by the Food and Drug Administration. There are many other medications and therapies for Parkinson's disease developed outside the U.S. that are not included in this report. To read the full PhRMA report, visit www.phrma.org/parkinsons-disease-2014.

This statement has been reprinted in its entirety with permission from Parkinson's Action Network. To learn more about PAN visit www.parkinsonaction.org.

Leave the Brain Out of It: Spinal Stimulation Could Offer an Alternative to Treat Parkinson's Motor Symptoms

Deep brain stimulation is a game changer for many Parkinson's disease (PD) patients. This therapy can alleviate motor symptoms and improve quality of life, but it does require brain surgery and is not a possibility for all people with PD.

A group of researchers from Duke University and the Edmond and Lily Safra Institute of Neuroscience of Natal in Brazil is working toward the same end result without the need for such an invasive procedure. These investigators made a splash earlier this year when they published in Scientific Reports that spinal cord stimulation in pre-clinical models improved motor symptoms and showed neuronal protection.

The Michael J. Fox Foundation (MJFF) did not fund that study, but has funded research from this same group of investigators to test spinal stimulation in a more advanced model. The MJFF-supported study is not testing the neuroprotective effect.

"This is an exciting time for, what we call, neuromodulation," says Maurizio Facheris, MD, MSc, associate director of research programs at MJFF. "While deep brain stimulation has helped many people living with Parkinson's disease, there are limitations to its use. Spinal stimulation could extend this therapeutic approach to many more."

For deep brain stimulation (DBS), a surgeon implants a thin electrode into the brain, targeting motor circuits that are not functioning properly. Small electrical pulses from a device similar to a cardiac pacemaker block the signals that cause some Parkinson's motor symptoms. Spinal stimulation uses the same technique, but rather than blocking the signals where they begin, the therapy blocks them further downstream. The electrodes are implanted in the dura, the outermost of three layers that surround the spinal cord.

Spinal cord stimulation is already used to treat chronic pain. Researchers are fine-tuning the application to work on the neurons that misfire to create Parkinson's motor symptoms. If successful, this procedure would be an alternative for patients who may not be able to have DBS because of vascular problems, mood disorders or aversion to brain surgery.

Through another grant, MJFF is supporting researchers from the University of California, San Francisco to develop a method to record brain activity during DBS so the stimulation can take place only when needed instead of continuously. The same enhancements could be used in spinal stimulation.

This article was reprinted in its entirety from FOXFEED BLOG with permission from The Michael J Fox Foundation for Parkinson's Research, posted March 10, 2014. For more information about MJFF visit www.michaeljfox.org.

Salivary Gland Biopsy Shows Promise to Helping Diagnose Parkinson's

A simple outpatient procedure that involves obtaining a tissue sample may help diagnose Parkinson's disease (PD) in the future, according to a new study in the journal *Neurology*. Using the technique, researchers diagnosed the disease correctly in a small group of people with PD about 75 percent of the time.

Currently, there is no objective biological test (such as a blood test) to diagnose PD. Instead, doctors diagnose the disease clinically by observing people's symptoms. The accuracy of such a diagnosis depends on the training of the diagnosing physician (better if diagnosed by a trained neurologist than an internist) and the duration of the clinical follow up when the diagnosis is made (the longer, the more accurate).

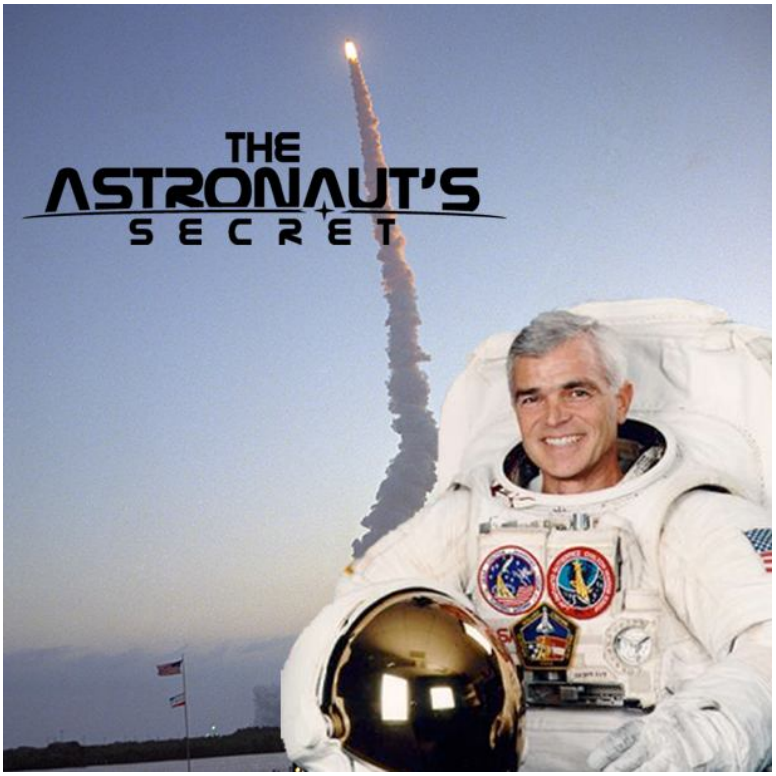
The only way to definitively identify Parkinson's is to demonstrate the presence of Lewy bodies, abnormal clumps of alpha-synuclein protein, in the brains of people with PD at autopsy. But autopsies have also shown that people with advanced PD have Lewy bodies in other areas of the body, for example, in the nerve cells of a salivary gland below the floor of the mouth, called the submandibular gland.

Researcher Charles Adler, M.D., Ph.D., at the Mayo Clinic in Scottsdale, AZ, and his colleagues wondered whether people living with PD also have Lewy bodies in their submandibular glands, and if doctors could perhaps diagnose the disease by testing tissue from the gland. He and his team performed a procedure called a needle core biopsy of the submandibular glands in 15 people who had PD for five or more years. The researchers numbed an area on the neck (just under the lower jaw) with local anesthetic, and then removed small pieces of salivary gland tissue through a hollow needle inserted into the skin. They examined the tissue sections with a microscope for signs of Lewy bodies.

Results

- Twelve biopsies (12 out of 15) included tissue from the submandibular gland.
- 75 percent (nine out of 12) of the biopsies from the submandibular gland had Lewy bodies, consistent with PD.
- Side effects of the procedure were minimal. Five people reported a swollen cheek, sore throat, excess fluid at the biopsy site, swelling under the chin, or slight bleeding/swelling/bruising under the jaw.

Continued on page 6



YOU ARE INVITED TO A SPECIAL SCREENING OF

THE ASTRONAUT'S SECRET

Thursday, April 17, 2014
7:30 pm

Houston Marq'e Stadium 23 & IMAX
7600 Katy Freeway Houston, TX

Honorary Event Chairs:
The Honorable and Mrs. George H.W. Bush

Join us for the special screening and stay for an exciting Q&A with astronaut Rich Clifford and the film's director, Zach Jankovic!

TICKETS: $50 includes admission & refreshments

No tickets will be sold at the door. Please purchase tickets in advance. If you would like to attend, contact the HAPS office at 713-313-1621 or nicholls@hapsonline.org. Will call opens at 6:30 pm. Please arrive early to pick up your tickets.

Benefitting HAPS and
Parkinson's Disease Center and Movement Disorders Clinic,
Baylor College of Medicine, Department of Neurology.

Sponsored in part by ucb

Gland Biopsy continued from page 5

What Does It Mean?

This small pilot study suggests that a needle core biopsy of the submandibular gland may one day help to definitively diagnose PD in living people. The noninvasive technique confirmed the diagnosis of PD based on clinical symptoms 75 percent of the time (when a submandibular tissue was indeed sampled), with minimal side effects.

The ability to diagnose Parkinson's with a test that goes beyond clinical observation would be a significant achievement in the fight against PD. It could improve diagnosis and clinical care, and advance research.

For example, before a person decides to undergo an invasive treatment such as deep brain stimulation, a biopsy could confirm that they actually have PD and could therefore benefit from the procedure. Also, the test could help to ensure that people who don't actually have PD, would not be selected for PD clinical studies since they could skew results.

This study has several limitations. First, only people who had PD for five or more years were included. At that stage, the physician's clinical diagnosis is often correct. Future study should focus on people with shorter disease duration to see whether this test may help establish a diagnosis of PD early, or maybe even identify people at risk for PD. Second, this study did not include healthy control subjects or people with PD-like diseases for comparison to the people with clinically diagnosed PD, but this data was available from a previous study. And finally, as a pilot study, only 15 people with PD were included.

Now that the researchers have obtained some promising results in this small group, they can expand their study to include controls, people with PD-like diseases, and larger numbers of people with early and advanced PD. Hopefully, pushing the needle further in our efforts to diagnose and cure Parkinson's.

This article was originally published as part of "Parkinson's Science News: What Does it Mean?" on the Parkinson's Disease Foundation (PDF) website on March 20, 2014. It is reprinted, in its entirety, with permission from PDF. For other science news, please visit www.pdf.org/science_news.

CONTRIBUTIONS

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Without the continued support of our donors, none of our programs or services would be possible.

IN MEMORY

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While we make every effort to be accurate and thorough, it is possible to accidently omit or misspell a name. Please contact the HAPS office with corrections.

Thirteen year old Jacob Rosenberg, son of HAPS Advisory Board member Jeff Rosenberg, recently had his Bar Mitzvah and decided he would like to help make a difference in the lives of people with Parkinson's disease by donating a portion of the monetary gifts to HAPS. Jacob sent in a major contribution totaling $1,148 in honor of his grandfather, Ronald Suchart, who is living with Parkinson's and in memory of his great grandmother, Lily Rosenberg, who had Parkinson's. HAPS thanks Jacob for his generosity and the entire Rosenberg family for supporting HAPS' efforts to improve the lives of families living with the disease.

Roslyn Waechter & Vernell Ireland

On March 18th, nearly 80 people attended a celebratory retirement luncheon to honor former PFHC President Roslyn Waechter, Vice President Vernell Ireland and Newsletter Editor Sarah Malcolm for their years of service and dedication to Parkinson Foundation of Harris County which ceased operations in March. They have given countless hours to the PD community by volunteering their time to a cause they are all so passionate about. Many thanks to Roslyn, Vernell, Sarah and the many other devoted volunteers who helped make PFHC such a worthwhile organization.

Houston AreA PArkinson society