



Parkinson's Institute  
and Clinical Center

# Leading with Compassionate Care: *Stories and Updates*

**IN THIS  
ISSUE**

- 1 Personal journey of Jim & Guila Pollock
- 2 From our CEO & Ways to Give

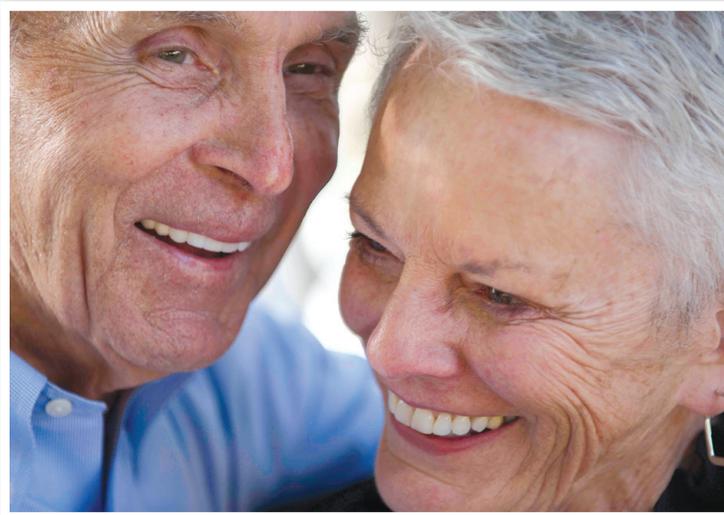
- 3 Introducing Dr. Santiago & Celebrating 30 years
- 4 Spotlight on Research

## Remaining grateful despite Parkinson's

Jim Pollock still says “I love you” to his wife Guila before heading out the door, however difficult it is to get the words out. His mobility and use of language is limited due to Parkinson's, but he continues to offer gestures of love. For Jim, family was bedrock to his life before his diagnosis—and all the more since.

Nearly ten years ago a doctor asked Jim, formerly a successful athlete as well as hunter and fisherman, about what was most important in his life. This conversation came on the heels of a speech irregularity for which Jim sought an answer. Jim identified faith, family and playing the banjo as most important. Weeks later, when a Parkinson's diagnosis became reality, the same doctor said, **“What you said is most important to you in life will be critical to your success through this.”**

**Jim and Guila include the Parkinson's Institute and Clinical Center as critical to his success as well.** The Pollocks feel known by, even friends with, their doctors. They are cared for along the emotional journey of living with Parkinson's,



**“I don't know of any other healthcare organization that provides the level of compassionate, coordinated care that we get at the Institute.”**

not just the physical one. Questions are answered directly and quickly and help is completely coordinated with other specialists who know Parkinson's well.

**“Not only does Jim get good care at the Institute, but they attract the most talented doctors and scientists,”** Guila says. “And they place such a huge value on research and clinical trials.” One of these

trials Jim was first to test at the Institute—using Botox as a way to improve mobility in Parkinson's patients. It resulted in significant improvement to the use of his hands and feet. “The way the Parkinson's Institute and Clinical Center uses research is inspiring,” adds Guila.

“Inspired” is a word Jim and Guila feel after all their appointments at the Institute. **“Every time we see doctors there, they will always encourage Jim and celebrate even his smallest wins,”** Guila says. Optimism comes from deep within the Pollock couple as well, who credit their faith in God and support from five children and ten grandchildren. **“Parkinson's is hard,” Guila**

*Continued on page 2*

## From our CEO

Dear Parkinson's Institute family,

We're channeling great energy toward the vision of the Parkinson's Institute and Clinical Center as we kick off 2018. Let me share a few areas fueling our excitement and optimism.

I'm honored to be joined by new Chief Medical Officer at the Institute, Dr. Anthony Santiago. His passion for putting patients first made him an obvious fit for the Parkinson's Institute and Clinical Center. I'm encouraged by his alignment with our vision as well as his immense talent to help accomplish it.

We have some critical research about Parkinson's psychosis, which can manifest itself in hallucinations and delusions in up to 50 percent of patients. We know this can be incredibly challenging for patients and caregivers alike, and unfortunately, these symptoms are often under-reported. But once consulted, a health care provider can often help customize medication to help treat these symptoms.

For over 30 years we have been groundbreaking together. 2018 will be no exception. We exist to take care of our patients and we do what is best for them first. Your support and financial contributions allow us the capacity to pursue this patient-first model. Thank you.



Carrolee Barlow,  
MD, PhD  
*Chief Executive Officer*

*Continued from page 1*

admits. **“It’s a horrible disease.** But when we got the diagnosis, we decided we wouldn’t bemoan what we couldn’t do anymore. Instead, we’d look with gratitude on all that we’d been given and all that we are still able to do.”

**“We’re both just so excited for the future of the Institute,”** she continues. “The treatment that patients like Jim receive is completely customized to his specific condition. I don’t doubt that our gifts go exactly where they say they do. To help current and future patients.”



**More Talk! More Walk!**  
**Saturday, May 19th, 2018**  
**Baylands Park - Sunnyvale, CA**

Lace up your walking shoes and join Parkinson's Institute and Clinical Center for the fourth annual *More Talk! More Walk!* fundraiser. Together, we'll walk the beautiful Baylands Park in Sunnyvale, CA to raise critically important funding for world-class care and cutting-edge research.

**Individuals and teams are welcomed!**

**For more details, go to**  
[www.moretalkmorewalk.org](http://www.moretalkmorewalk.org)

## Giving can take many shapes

Both the level of compassionate care our patients receive daily, as well as the world-class research we perform, is unique to Parkinson's Institute and Clinical Center and only made possible through your support. We want you to know about the variety of ways you can give to the Institute.

- **Write a check or use your credit card today**
- **Give a gift from your Donor Advised Fund or Family Foundation**
- **Gift a gift of stock or other appreciated assets**
- **Have your gift matched by your employer**
- **Include us in your will or estate plans**

# Personal and Precise Medicine: Welcoming Dr. Anthony Santiago

We are pleased to introduce Dr. Anthony Santiago, the new Chief Medical Officer at the Parkinson's Institute and Clinical Center. Dr. Santiago's emphasis in research and treatment of movement disorders spans nearly his entire career thus far. He most recently served as the Chief Medical Officer and member of the Board of Directors for Pathways Group, Inc., a network of professionals and companies dedicated to improving the lives of people with neurodegenerative disorders. A detailed bio can be found on the Institute's homepage.



Dr. Santiago's concern for those affected by movement disorders began long before medical school. **"Movement disorders affected my family in many ways," he says. "I consider it a gift to have experienced what my family did, as it prepared me for this future."** At age 16, he was already performing grant-funded movement disorder research and he says that not long after, "I knew that I wanted to invest my entire career treating patients with Parkinson's and other movement disorders."

Dr. Santiago threw himself into his career, caring for 1,000+ patients

at a time, starting a Parkinson's center and training new fellows. He soon realized he was one of the few doctors in the country who specialized in movement disorders—and risked burnout. After holding several significant roles with institutions throughout the country, we are honored that he brings his vast expertise and dedication to the patients and staff at the Parkinson's Institute and Clinical Center.

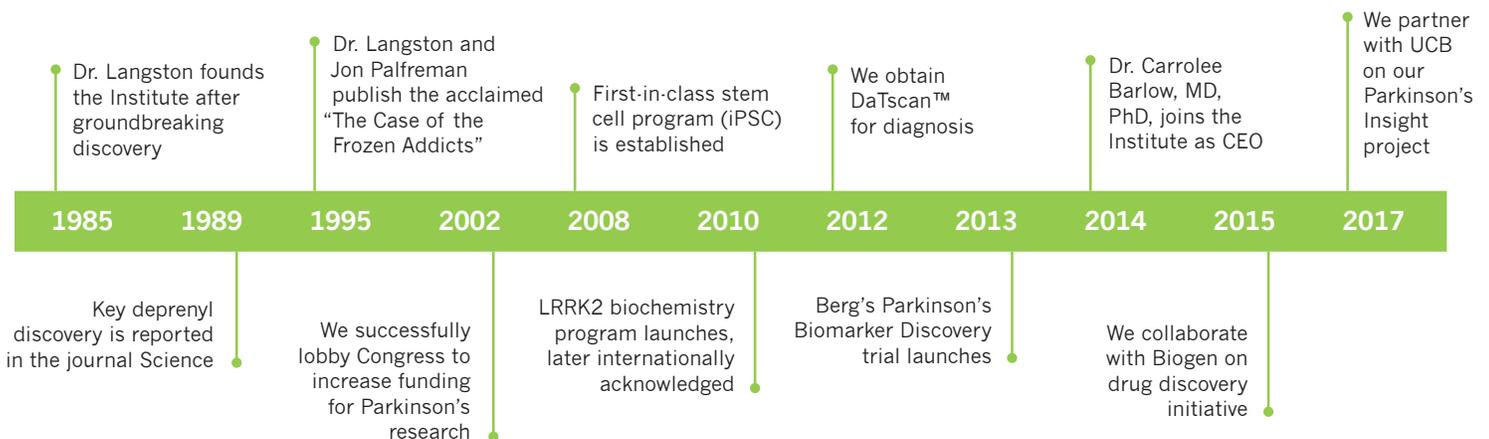
Dr. Santiago begins with virtualized medicine as a top focus, seeking to bring the Parkinson's Institute and Clinical Center across state lines in partnership with local physicians. Those who suffer from Parkinson's

but live in remote areas of the country often do not have access to professionals who specialize in the disease. **"We want to change that by creating a virtual care model that allows patients to access specialists regardless of their geography,"** Dr. Santiago explains.

He is also passionate about training the next generation of scientists and clinicians in the field of movement disorders—a field needing more practitioners. Dr. Santiago recently hired the Institute's new Director of Clinical Studies, Dr. Andres Alvarez-Pinzon, and new doctor Kristin Andruska. **"They are both top in their field, and they align well with our vision that the Institute belongs to our patients,"** he says. **"We see our patients as partners in this process."**

**We are thrilled that Dr. Santiago is now a partner and advocate for our patients.** "I'm looking forward to bringing 21st century, personalized, precision-medicine to the field of neurology," Dr. Santiago says. "If you are able to give financially, focus your investment on organizations that put their patients first in everything they do. This is why I think the Institute is the right place."

## 30+ Years of Discovery and Care



# Understanding Parkinson's Disease Psychosis

Imagine learning to care for a loved one with Parkinson's disease (PD), which is a neurodegenerative brain disorder that affects nearly one million people in the United States. He may move slowly or is rigid, lose his balance easily or shake uncontrollably while resting, which are common symptoms of PD.

But then other symptoms begin to occur. He starts asking why the kids are in the car, but your kids have grown up and moved away. Or he thinks someone is watching him. And, of course, no one is there.

Hallucinations and delusions like these are symptoms of Parkinson's disease psychosis, which occurs in about 50 percent of people with PD at some point during their illness.

Sometimes described as “tricks” played by the brain, hallucinations can cause a person to see, hear, feel, smell or even taste something that isn't real. A person with hallucinations may say they see people or animals that aren't there. As their hallucinations become more frequent, they may not be able to tell what's real and what's imagined and may react to things that aren't real.

Delusions occur less frequently than hallucinations and are generally more difficult to treat. Delusions are fixed, false beliefs not supported by evidence and often have paranoid themes. A common delusion that occurs in people with Parkinson's is that their partner is having an affair, even if they have been married for decades and their spouse is with them nearly all of the time.

When a loved one is experiencing hallucinations and delusions, it can add more frustration to the already challenging physical limitations of Parkinson's. Research has found that hallucinations and delusions can lead to increased distress, greater responsibility for caregivers, and even nursing home placement. Yet, as difficult and distressing as these hallucinations and delusions may be, only about 10 percent to 20 percent of patients who have hallucinations or delusions associated with PD proactively report the symptoms to their health care providers.

That may be because they don't understand that these symptoms are associated with PD or are embarrassed to report that they are experiencing visions and

false beliefs. Sometimes these “invisible” symptoms can cause more problems than the motor issues—especially if people with Parkinson's don't seek help. Hallucinations and delusions usually appear later in the disease's progression and often catch caregivers by surprise if they and the doctor are focused on motor symptoms, which are easier to identify.

## Causes of Parkinson's disease psychosis

The cause of hallucinations and delusions associated with Parkinson's is not clearly understood. The drugs commonly used to treat PD, which raise dopamine levels to improve motor control, can cause physical and chemical changes in the brain that may lead to hallucinations and delusions. In addition, the natural progression of Parkinson's disease may cause brain changes that trigger symptoms.

## Treatment for Parkinson's disease psychosis

A health care provider can help to identify hallucinations and delusions associated with Parkinson's, monitor signs that symptoms may be progressing, and offer ways to help manage any related challenges.

The first step is for the physician to confirm that the hallucinations and delusions are caused by Parkinson's disease by eliminating other possible causes. Once the diagnosis is made, the health care provider will decide how to treat the symptoms. Treatment may involve adjusting or switching PD medications. Antipsychotic medications also may be used, including an FDA-approved treatment option specifically for hallucinations and delusions associated with Parkinson's disease that may be appropriate for some people.



**This article was medically reviewed by Karen Elta Anderson, MD, Neuropsychiatrist, MedStar Georgetown University Hospital, Washington, DC and originally posted at [HealthyWomen.org](https://www.healthywomen.org)**