



NEWS FROM THE PARKINSON'S INSTITUTE AND CLINICAL CENTER

# causecarecure

NEWSLETTER  
Spring 2012

STORIES TO READ

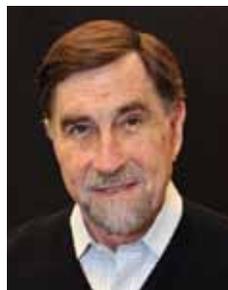
- 1 Great Doctors Honored
- 2 The Never Bored Board Chair
- 3 A Patient's Story on Exercise
- 4 Research Partners at The Institute
- 6 Crumbs from the Cookie Jar
- 7 Q & A with Dr. Brandabur
- 8 Patients Tell Their Story

PROVIDING THE BEST POSSIBLE PATIENT CARE

## Great Doctors at The Parkinson's Institute

*Great doctors, great care and great research are all part of what make The Parkinson's Institute such a remarkable place. The Institute has had two physicians recently honored by peers. We are pleased to share these honors with you.*

### Dr. Langston Receives The Pritzker Award



Dr. J. William Langston

Dr. Langston - CEO, Scientific Director and clinician at The Parkinson's Institute - has been awarded the Robert M. Pritzker Award by the Michael J. Fox Foundation for his lifetime leadership in the Parkinson's disease (PD) field. The award

was presented by Mr. Fox.

In accepting the Pritzker Award, Dr. Langston remarked, "As someone who has spent their career working on Parkinson's disease, I am honored and inspired to have been selected for the Pritzker Prize. Indeed, it adds a powerful incentive to all of us here at The Parkinson's Institute to accelerate our efforts more than ever to solve this most difficult disease."

Dr. Langston founded The Parkinson's Institute to create an environment that takes an integrated approach to basic and clinical research and patient care. The Parkinson's Institute is the only independent, nonprofit Institute in the United States that combines patient care and research. The Institute is focused solely on Parkinson's

disease - including patient care and research into the cause of and cure for this disease.

During his career, Dr. Langston has made fundamental contributions to the understanding of the role of environmental factors in the onset and progression of Parkinson's disease. Since his landmark discovery of the biological effects of MPTP, a neurotoxin widely used in the study of Parkinson's disease, Dr. Langston continues to work toward a cure through research on the study of mechanisms of neuronal degeneration, the etiology of Parkinson's disease and the development of new strategies to slow or halt disease progression. He is the author or co-author of more than 350 publications in the field that have led to greater understanding of Parkinson's disease and progress towards a cure.

This prestigious prize is named in honor of the late Robert A. Pritzker, a renowned industrialist, entrepreneur and philanthropist who had Parkinson's disease.

### Dr. Tanner Honored as 2012 Movement Disorders Researcher



Caroline M. Tanner,  
MD, PhD

Dr. Tanner, Director of Clinical Research and clinician at The Parkinson's Institute, has been awarded the 2012 Movement Disorders Research Award by the American Academy of Neurology (AAN).

*continued on page 5*





Tom Follett

Chair, Board of Directors



The Parkinson's Institute and Clinical Center

BOARD OF DIRECTORS

Thomas D. Follett  
Chair of the Board

Thomas E. Bailard  
Board Member

Dan Clevenger, DDS  
Board Member

Susan J. Foster  
Board Member

Kenneth Graham  
Board Member

Judith A. Hemberger, PhD  
Board Member

Robert Howells  
Treasurer

J. William Langston, MD  
CEO, Board Member

Vernon Norviel  
Board Member

Peter C. Nosler  
Vice Chairman

# The Board Chair is Never Bored

*The last time I was asked to write a piece for The Institute's newsletter, I expressed my pride in leading this organization as Chair of the Board of Directors. The last few months have given me more reason to be proud of our work. I am also humbled by the opportunity to work with such dedicated people every day.*

*In April, I was honored to go to New York City and see our CEO, Dr. Bill Langston, receive the Pritzker Award for his Leadership in Parkinson's disease Research. I was able to meet Michael J.*

*Fox who presented the Award to Dr. Langston. It was inspiring to see Dr. Langston, whom I work with virtually every day, through the eyes of other leaders in the PD field. Further, I was proud of the recognition Bill Langston and The Parkinson's Institute received with regards to his life's work.*

*Just a few days later, Dr. Caroline Tanner received an award from the American Academy of Neurology as Movement Disorder Researcher of the Year. That was exciting to learn about. Last year, Dr. Tanner and her team here at The Institute published more than half a dozen papers in an attempt to understand the cause of PD. The applications of this research are immense. For governmental agencies, some applications include the examination the toxicity of pesticides, solvents and other chemicals that have strong indications of causing PD. Pharmaceutical firms can apply this research to see the effect of drugs on PD. Also, researchers gain key insights into understanding the mysteries behind Parkinson's disease. Dr. Tanner is a leader*

*in this field and dedicated to finding out why people like me—and perhaps you—have PD.*

*After such festivities, we all come back to The Parkinson's Institute. There is "real work" to do: recruit new Board members, review finances, help with fundraising, guide Board members through long range decisions and offer advice to staff. The work is often challenging, often fun and always very satisfying.*

*On a recent Saturday afternoon, a funny thing happened; I drove by The Institute only to*

*notice a large number of cars in the parking lot. I thought, did I miss a meeting? So I stopped, knocked on the door and a young researcher came to it and let me in. As I inquired about the activities in The Institute, she explained that nine researchers were working in the Lab. They were looking in the microscopes, examining the Petri dishes and working in all kinds of ways. I told them it was a beautiful day, so why were they in the Lab? One of the researchers said, "PD doesn't stop, and neither do we." This team illustrates the dedication necessary to move towards finding a cure for PD. Yes, I am proud of this team. As a reader of this newsletter, I want you to know whether it is Bill Langston or Carlie Tanner or Gloria at the reception desk—we all want you to be better, we all want to find better treatments and find a cure. We are working for you.*

Best Regards,

Tom Follett  
Chair, Board of Directors

**PD doesn't stop,  
and neither do we.**

cause

# Wonderful Benefits: One Patient's Story of Life with Exercise

**At The Parkinson's Institute, we believe that exercise is a vital component of our care program. It is prescribed by our clinicians as often as any medication. This is an original story written by a patient of The Parkinson's Institute.**

*By Tracy Herrick,  
Patient and Daily Exerciser*

When I was originally diagnosed with PD, I felt my life would become an endless cycle of monotony. That was nine years ago, and life has been the same with one



exception. My doctor told me to exercise, and The Parkinson's Institute has an excellent exercise program. But it was a distance from our home, and I wanted a program closer to our home.

So my wife and I joined an exercise club to see if a more rigorous program would

be of even more benefit. I didn't buy a fancy exercise outfit; it really wasn't necessary. Anyway, my wife and I were the oldest people in the place, and that didn't bother me either.

Our current exercise club is filled with all of those wonderful young people who struggle to push and pull the machines and run on a moving track. Their intensity during exercise is similar to how they handle their whole lives. I knew I couldn't do that, and my good counsel along with my doctor at The Institute told me not to worry about being intense – just plug along at a comfortable speed and a moderate lifting of weight and resistance machines. So, I walked into the exercise room, a bit intimidated by the equipment. Somebody showed me how everything worked. I was off to the races.

I was truly amazed at myself after about thirty five minutes of workout. It was as if a great weight had been lifted from my shoulders. I felt a bit like my old self. I still regard my exercise time as something I wish would not be necessary, but there it is. The wonderful benefits are worth every minute.

Then, two years ago, I started to ride my bicycle to make errands and visit friends, and to go to my club for lunch. The feeling of riding a bicycle remains analogous to the comfortable, easy glide of a low flying



---

**I felt a bit like my old self.  
The wonderful benefits are  
worth every minute.**

---

bird. In addition, I never have to pay a parking ticket. Biking allows me to feel like a kid all over again.

But the effect of exercise seemed to have greater implications. It was easy to move as I stepped down from my bike and started to walk again. It was as if I were with very little affliction. I really liked that.

The Parkinson's Institute has a full program of exercise classes to choose from to make sure you are following doctor's orders! Please consult your doctor before beginning any exercise program. For more information about classes, please call (408) 734-2800.



## McAfee Golf Tournament

The Parkinson's Institute was honored to be the beneficiary of the First Annual McAfee Software Charity Golf Tournament. The event raised more than \$50,000 for The Parkinson's Institute. Pictured here is McAfee Software Co-President Todd Gebhart presenting a really big check to The Institute's Dr. Bill Langston. On behalf of the patients who will be helped by this support—**We thank everyone at McAfee Software!**



# Research at **The PI**



RESEARCH THAT MATTERS

## The Parkinson's Institute's Prominent Partners

What do the California Institute for Regenerative Medicine, Michael J. Fox Foundation, Department of Defense – U.S. Army Research, National Institute of Health and the University of Columbia all have in common? They are just some of the dozens of public and private organizations working with The Parkinson's Institute to find the causes, methods of care and potential cures for Parkinson's disease.

The Parkinson's Institute was founded with the belief that patient care and research must go hand-in-hand in order to provide the most comprehensive care possible and to accelerate that research.

Grants from some of the most prominent names in scientific philanthropy allow our scientists to perform cutting-edge research, searching for game-changing discoveries

### **The researchers at The Parkinson's Institute are working to find the answers to your questions.**

to advance the fight against Parkinson's disease. So whether it is researching stem cells, studying DNA and the LRRK2 gene, exposure to solvents, pesticides and other toxins in the environment or translational

drug development, the researchers at The Parkinson's Institute are working to find the answers to your questions.

We don't do it alone. We work with more than a dozen scientific funders as well as receive vital financial support from patients, individuals, corporations and organizations which helps to fund our equipment needs, our clinic and all-important patient care.

The next time you are at The Parkinson's Institute, we invite you to look over our Wall of Research to learn what our scientists are researching and what they are discovering.



**What does Parkinson's Disease research look like? These images capture some of the research that is conducted inside the laboratories at The Parkinson's Institute. Harder to capture is the dedication and passion these scientists have for finding the causes of and the cure for Parkinson's Disease.**



# Unity Walk 2012



Dr. Sam Goldman of The Parkinson's Institute and more than 10,000 walkers came together in New York City on Saturday, April 28th for the Annual Unity Walk for Parkinson's disease. The Parkinson's Institute is one of seven PD organizations in the United States which is supported by the Unity Walk, coordinated by The Parkinson Alliance. These funds go directly to research and are making a significant difference for those with Parkinson's disease. The Central Park Walk is supported by dozens of local walks in small and large cities throughout the country. Everyone at The Parkinson's Institute truly appreciates those who walked. See you in 2013!

## Great Doctors

*continued from page 1*

This prize is being given in recognition of her outstanding achievements in movement disorders research – the area of neurology that deals with Parkinson's disease most specifically. Notably, Dr. Tanner is the first woman to ever receive this prestigious award.

"I am honored to receive this recognition from the American Academy of Neurology, an organization that has been important to my career since my residency," said Dr. Tanner. "With my colleagues at The Parkinson's Institute and our many collaborators world-wide, I have dedicated my career to understanding the causes of Parkinson's disease and to developing better treatments, with the future goal of applying this knowledge to prevent or cure Parkinson's disease. Parkinson's disease is already the

second most common neurodegenerative disease in developed countries. It will become increasingly common worldwide in this century, highlighting the urgency of our task. Ultimately, my research is inspired by the courage and insight of my patients, who are always foremost in my mind."

The Award is sponsored by the American Academy of Neurology, the Parkinson's Disease Foundation and the Academy's Movement Disorders Section and endowed by the Parkinson's Disease Foundation.

***There are five clinicians who see patients at The Parkinson's Institute. Each of them are outstanding doctors who care deeply about their patients. If you would like to see Dr. Langston, Dr. Tanner, Dr. Brandabur, Dr. Liang or Dr. Tetrud, please call The Institute at (408) 734-2800.***

## RESOURCES FOR THOSE LIVING WITH PD

[WWW.PPSG.ORG](http://WWW.PPSG.ORG)  
PARKINSON'S PATIENTS SUPPORT GROUPS

[WWW.PDTRIALS.ORG](http://WWW.PDTRIALS.ORG)  
PARKINSON'S CLINICAL TRIALS

[WWW.COASILICONVALLEY.COM](http://WWW.COASILICONVALLEY.COM)  
COUNCIL ON AGING SILICON VALLEY

[WWW.CARING.COM](http://WWW.CARING.COM)  
HELPING YOU HELP YOUR PARENTS

[WWW.NLM.NIH.GOV/MEDLINEPLUS/PARKINSONSDISEASE.HTML](http://WWW.NLM.NIH.GOV/MEDLINEPLUS/PARKINSONSDISEASE.HTML)  
MEDLINE PLUS

[WWW.SVILC.ORG](http://WWW.SVILC.ORG)  
SILICON VALLEY INDEPENDENT LIVING CENTER



# CRUMBS FROM THE COOKIE JAR

By Gloria Goldstein

## ENUFF 2 MAKE U LOL?

I am beginning to think the cell phone has taken the place of cigarettes. These little devices seem to be as addictive!

I was in a restaurant having dinner recently, and where once people leaned back after a big meal and pulled out a pack of cigarettes, they now pick up their cell phone and start texting.

At one table of two adults and two children, the children were fussing with each other as each of their parents were engrossed with their cell phones. They weren't having any kind of family communication.

Has the art of holding a conversation disappeared? And why would you text when you can talk? What on earth has texting done to spelling and grammar? It is enough to make me LOL!

See you soon!

*Gloria Goldstein has worked at The Parkinson's Institute since 1999. She is the "heart & soul" of the place. She is the "cheery voice on the phone, the smiling face in the lobby, the chief cookie dealer and the poet laureate of The Institute.*



# Upcoming Seminars and Classes at The PI

**MAY 31: Financial Planning Seminar—Advice When You Need It**  
6:00 – 7:30 pm

**JUNE 11: Support Groups—Getting By With a Little Help From Friends**  
1:30 – 3:30 pm

**JUNE 26: Newly Diagnosed Seminar—Facts, Fiction & What You Need to Know about PD** • 1:30 – 3:30 pm

**JULY 9: Vision and PD** • 1:30 – 3:30 pm

- Gait & Balance Class
- pdDance: Poetry in Motion
- Weight Training for PD
- LSVT Class PD Choir

CHECK WEBSITE FOR DAYS AND TIMES OF CLASSES

**PLEASE RSVP TO (408) 734-2800. ALL SEMINARS ARE FREE OF CHARGE!**



Photo by: Joy Sorenson

Robin Katsaros

## Parkinson's Awareness Month Celebrated

More than 100 people gathered at the Bike Shop at 359 State Street in Los Altos for the "April is National Parkinson's Awareness Month" event. Sponsored by Parkinson's Action Network's California Assistant State Director Robin Katsaros, the event included several highlights, such as an educational component, proclamations from the mayors of Los Altos and Los Altos Hills, and a panel from the Parkinson's Quilt Project organized by the Parkinson's Disease Foundation. Also, the event featured a presentation by The Parkinson's Institute's Dr. Langston. Dr. Langston was honored for receiving the Pritzker Award for Lifetime Achievement in Parkinson's Research.

## HAVE YOU BEEN DIAGNOSED WITH PARKINSON'S DISEASE?

Participants may receive free:

- Study-Related Physical & Mental Exams by Movement Disorder Specialists
- Study-Related Medications
- Study-Related Laboratory Tests
- Travel Reimbursement

## JOIN A CLINICAL TRIAL!

For more information, contact our clinical trials coordinators at (408) 734-2800, [trials@thepi.org](mailto:trials@thepi.org), or visit us online at [www.thepi.org/ClinicalTrials](http://www.thepi.org/ClinicalTrials)

# The Doctor Is In

By Melanie M. Brandabur, MD

**The Doctor Is In is a regular column in The Parkinson's Institute Newsletter. Our clinicians will answer your questions about PD, current and new care programs and other topics of interest.**



**The Doctor Is In questions are answered in this issue by Melanie Brandabur, MD. Dr. Brandabur is a neurologist and movement disorder specialist who sees patients at The Parkinson's Institute's Clinic; she is also Director of the Clinic.**

Melanie M. Brandabur, MD **Q. What can I do to make my time with my neurologist as efficient as possible? When my doctor asks how I am, how much detail does he/she want?**

There is a great deal that a patient can do to get the most out of the appointment with the neurologist. Bring a list of current PD medications and the times at which they are taken. Bring a list of all other current medications and supplements. Mostly we want information that would pertain directly to the PD and its symptoms or treatment.

## Questions you may be asked by your Neurologist:

1. In general, how are my PD symptoms compared to my last visit?
2. Have any major illnesses, new diagnoses, hospitalizations, surgeries or changes in living situation occurred since my last visit?
3. Is the PD medication working smoothly over the course of the day?
4. Is the medication wearing off before the next dose? How long does each dose last? What symptoms emerge as the medication wears off? Toe curling, tremor, muscle cramps, difficulty walking, anxiety, pain?
5. Are there any symptoms that could be due to medications? Involuntary movements? Hallucinations? Low blood pressure/dizziness? Compulsive behavior? Daytime sleepiness?
6. Did I have any falls since my last visit? How did they happen?
7. Do I have any trouble swallowing or speaking?
8. How is my mood? Any anxiety or depression?
9. How is my sleep? Any yelling or unusual activity during the night? Any snoring?
10. Do I have any new symptoms? Remember, anytime you experience a new symptom, try to see whether it relates to the timing of your PD medication (worse at the peak of dose effect 1-2 hours after the dose or immediately prior to the next dose).

**Q. I saw four doctors and it took more than two years before I was properly diagnosed. Why is it so hard to diagnose PD? What is being done to improve the diagnosis process?**

Most doctors are trained to recognize PD by looking for the four "cardinal features": tremor when the limb is at rest, rigidity, slowness of movement, and, later on in the disease, balance impairment. However, some patients with PD have tremor that occurs with action or in other situations besides resting and some patients have no tremor at all.

In addition, there are many conditions that are related to PD and have a similar presentation initially, but actually are entirely different diseases, such as Multiple Systems Atrophy (MSA) or Progressive Supranuclear Palsy (PSP). Patients with these disorders tend to have additional features such as profound changes in blood pressure, swallowing abnormalities or very loss of balance reflexes, leading to falls.



One way to improve the diagnosis process is to see a neurologist with additional training and experience in PD and other Movement Disorders, like the ones here at the PI. For the most part, these diagnoses

are made according to the history and neurologic examination of the patient by an experienced clinician.

A specialized brain scan, called a DAT scan, has recently become available and may provide some additional information in cases where there is a tremor and there is uncertainty as to whether or not it is caused by PD. However, the scan is not particularly helpful in differentiating related disorders, such as MSA or PSP, from one another.



## VOICES THAT MATTER

# Why I Support The PI

*These quotes, though unattributed, come from patients and family members of patients. All of them were asked “why do you support The Parkinson’s Institute?” These are edited for space. If you would like to tell us why you support The Parkinson’s Institute, please contact us at [info@thepi.org](mailto:info@thepi.org). Please put “Why I support” in the subject line.*

“I was raised to believe if you wanted something done right, you do it yourself. Well, I can’t do the medicine or the science, but I support The Parkinson’s Institute because I know they are doing it right. My care is great and I know I am benefitting from the doctors and scientists who work together.”



doctors in the world and together we were going to make my life better. I like the idea of being on a team, because I am not allowed to be a ‘bench warmer’. Every day I exercise, eat right and take better care of myself now than I used to. Parkinson’s is not easy, but somehow, it seems OK with the care I get at The Institute”.

“It begins when you walk in the door—from Gloria’s friendly welcome, to the nurses and everyone there, you can tell they care. The doctors are great, never in a rush—answering all my questions, really listening to me and my husband, working to figure out what is best. I just adore Marilyn; she works me hard but I know she wants me to feel good for as long as I can. We drive almost 2 hours to come here, but it is the best experience I have ever had with a doctor or clinic and I am 70 years young! After we make our co-pay, we leave an extra check. I know the gift is put to good use, making other patients feel good and get better.”



“I have been through a lot of revolutions here in the Silicon Valley. I have seen NASA, technology, computers, the internet all grow here, practically in my backyard. I think the smartest people in the country are in this building, working on my disease. I am ready for the PD revolution to happen at The Parkinson’s Institute. My gifts are my investment—someday soon there will be a PD revolution and I will get cured. How can I not support that”?



“One day I got 5 “asking letters” in the mail. They were for a lot of good causes, but the only check I wrote was for The Parkinson’s Institute. I have been a patient there for 4 years. I know how good the care is. I know that every single person is trying to get me better and find a cure. How can you not



“We love everybody at The Institute! I walked in there scared to death. My wife was practically in tears. Our family doctor sent me here when he couldn’t figure out what was wrong. They diagnosed me quickly but instead of feeling desperate, I felt like I had joined the best

support that? I feel like the life I save could be my own, or my daughters ... I do what I can to help them. I am glad I can help. “

*“After we make our co-pay, we leave an extra check. I know the gift is put to good use, making other patients feel good and get better.”*



**The  
Parkinson’s Institute  
and Clinical Center**

### CONTACT US:

The Parkinson’s Institute  
and Clinical Center  
675 Almanor Avenue  
Sunnyvale, CA 94085  
(408) 734-2800  
(800) 655-2273  
[trials@thepi.org](mailto:trials@thepi.org)  
[clinic@thepi.org](mailto:clinic@thepi.org)

### ONLINE:

#### Facebook:

The Parkinson’s Institute  
and Clinical Center

**Twitter:** pdffighter

### OFFICE HOURS:

Monday – Friday  
8:30am - 5:30pm  
[www.thepi.org](http://www.thepi.org)

This newsletter is a quarterly production of the Development Department at The Parkinson’s Institute. If you have comments or questions, please contact the Development Director, Mary Tunison at (408) 542-5606 or at [mtunison@thepi.org](mailto:mtunison@thepi.org).