



The  
Parkinson's Institute  
and Clinical Center

DECEMBER 2010



# causecarecure

## IN THIS ISSUE

- 1 Patient Spotlight
- 1 Surviving the Holidays
- 2 Message from the COO
- 3 Staff Spotlight
- 3 Researching Genetic Forms
- 4 Surviving the Holidays (cont.)
- 5 Volunteers Needed
- 6 Resistance Training
- 6 Running for PD
- 7 The PI Events

## PATIENT SPOTLIGHT

### Get Up and Go!

This is the motto Patricia Cooper lives by. Those words were pulled from the newspaper and stuck to the mirror in her bedroom so she can see them every morning. Patricia believes that every moment matters and she does her best to GO! Being diagnosed with Parkinson's disease two years ago has done nothing to slow her down or squelch her spirit. Participating in the exercise classes here at The PI, as well as a home routine and walking, have given her the energy she needs to live her life to the fullest.

In October, Patricia went skydiving for the first time. When asked why she went, Patricia said, "It was something I always wanted to do and there was no reason not to go." Patricia also enjoys parasailing and hot air balloon rides.



Patricia Cooper takes a leap!

Her advice to others with Parkinson's, "Don't give up. You can always do new things. Just get up and go!"

## HINTS AND TIPS FOR LIVING WITH PD

### Surviving the Holidays



The holidays can be an overwhelming time for the best of us, but having PD can add additional stress. To help you weather the season in top form we have queried our doctors and staff for a list of holiday tips, hints and wish lists.

#### **How to minimize the work if hosting a party:**

- If you usually do everything, ASK FOR HELP!

- Consider having someone else host this year. Offer to bring a favorite dish to the festivities, preferably one that you can make in advance.
- If you do host a party at your house, assign friends and family to be in charge of different aspects: one to help with tidying up, one to organize decorations or table setting, one to be in charge of the food, one for the beverages, etc.
- If you take on the entire event because nobody else does it as well as you, relax your standards!





Clyde Taylor  
Chief Operating Officer

# Letter From Our COO

Dear Friends,

As we close out 2010, I would like to introduce myself and wish all of our patients, their friends and families, donors and supporters of The Parkinson's Institute (The PI) a happy holiday season.

In August of this year, I joined The PI as Chief Operating Officer, taking responsibility for the day-to-day operations. As a non-profit, we must match research grants, patient fees, and donations with expenses, in order to balance the budget and keep the lights on. Ultimately, we seek ways to prevent PD and provide medical care to those affected by it. The PI has evolved into a key leader in the field of PD research and patient care, with our scientists and physicians at the leading edge of the fight against this disease.

For most people, the clinic is the primary face of The Institute, and it is unique in several respects. Because of the commitment of the organization, the Board of Directors, and our generous donors, we provide the highest standard of care for patients and their families. Our physicians are movement disorder specialists, and each patient receives specialized treatment resulting in longer, more thorough and comprehensive appointments. This quality of care costs far more than the patient fees collected. Where does the money come from to pay for this care? As you can see from the chart below, almost 60% of the money to operate the clinic comes from donations. We could not keep the clinic open without your steadfast support!

Another way to support the clinic is through participation in clinical trials. Clinical trials are valuable for several reasons:

- Allow patients access to new treatments.
- Facilitate approval of new drugs which may become available to all PD patients.
- Provide additional financial resources for clinic operation.

Along with many others, The PI researchers are working hard to find ways to prevent and treat the disease. Given the small size of The PI, and our limited financial resources, the impact of this Institute on Parkinson's research is truly remarkable. For 22 years, The PI's research has led the field; today, more than ever, our research is considered among the best in the world. We rank alongside giant, well-funded institutions like Stanford, Harvard, Johns Hopkins, and Georgetown. The PI is an extremely valuable and cost-effective resource in the battle against this terrible disease.

I know that I speak on behalf of everyone here at The PI when I say that we are very aware, every day, that the clock is ticking... the disease is advancing in our patients and in those yet to be diagnosed. As we continue our unwavering commitment to fight this disease, help us advance our mission by continuing your support. I encourage you to give a gift in honor of someone you love, investing in research and care this holiday season.

All the best,

Clyde Taylor  
Chief Operating Officer

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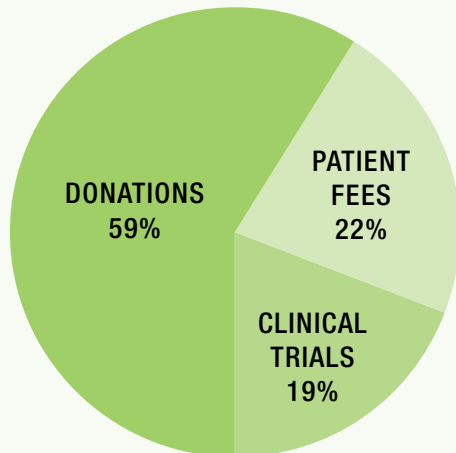
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Director of Clinical Research

Clyde Taylor  
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Clinic Medical Director



## STAFF HIGHLIGHT

# New Scientist Joins The Parkinson's Institute

Dr. Jeremy Nichols received his Ph.D. from the Microbiology and Molecular Genetics Department at the Medical College of Wisconsin. While there, he worked on a family of kinases involved in cellular proliferation, as well as on vaccinia virus infectivity. He undertook post-doctoral training at the Medical Research Council Protein Phosphorylation Unit in Dundee, Scotland, which is world renowned for its work on signal transduction by kinases. There he began his studies of LRRK2 and made several discoveries about the biology of LRRK2. In May 2010, he moved his family from Scotland to California and began his post here at The PI.



*"This is the right place and time to make great strides in studying inherited PD to search for therapeutics to treat all Parkinson's disease patients. This is why I come to work every day."*

Dr. Jeremy Nichols

## STEM CELL UPDATE

TPI has successfully created neurons, shown in green, with yellow showing those producing dopamine, bringing us one step closer to creating Parkinson's in a petri dish.

# Researching Genetic Forms of PD

This year, The PI welcomed Jeremy Nichols, PhD, to our Basic Research Department. His work focuses on LRRK2 (Leucine Rich Repeat Kinase 2), in which inherited mutations have been shown to cause Parkinson's disease (PD). Dr. Nichols is working on understanding the molecular role of LRRK2 in PD in order to develop preventative therapies. Current treatments focus on ways to regulate symptoms, but Dr. Nichols is seeking specific ways to prevent disease onset.

In 2004, it was discovered that mutations in the LRRK2 gene increased the risk factor for PD. Taking a multidisciplinary approach, Dr. Nichols is looking to understand how LRRK2 is regulated and which molecular pathways LRRK2 regulates. He has already helped define in vitro assays for LRRK2 as well as characterized important regulatory modifications on LRRK2.

LRRK2 belongs to a class of enzymes known as kinases, which have already been successfully targeted for development of specific drugs to treat diseases such as cancer. It is hoped that targeting LRRK2 in a similar manner will

result in treatments that could aid in delaying disease onset or improving patient well being. Dr. Nichols is helping to develop assays of LRRK2 that can be used in trials of drugs that specifically target LRRK2.

Working in conjunction with Birgitt Schuele, MD, Clinical Molecular Geneticist, at The PI, they will be focusing on understanding the basis for genetic causes of PD. Dr. Nichols has developed partnerships with industry, trying to turn small steps into leaps by leveraging resources, capabilities and common goals. In October, Dr. Nichols spoke about LRRK2 at the 2010 PD Therapeutics Conference held by the Michael J. Fox Foundation and the New York Academy of Sciences. Dr. Nichols has received starting funds as well as a grant from the Michael J. Fox Foundation, and continues to pursue funding to achieve his research objective – alleviate the disease symptoms.



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

# Join a Clinical Trial!

*Participants may receive free:*

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

**For more information, contact Liza Reys at 408-542-5626, [lreys@thepi.org](mailto:lreys@thepi.org), or visit us online at [www.thepi.org/ClinicalTrials](http://www.thepi.org/ClinicalTrials)**

## CRUMBS FROM GLORIA'S COOKIE JAR

The year seems to have brushed past me, and Christmas must be near because here I sit trying to sort my bills out of a towering pile of Christmas Catalogs and glossy Holiday Sale Papers that have slipped into hap hazard piles at my feet (oops!) hiding my bills. I waded through special offers from mattresses to manufactured homes, toys to telephones, imported cheese, cakes and candies to holiday menus that I need to pick up to make sure every bill is located. After struggling through this deluge of unsolicited "helpful hints" I find all my bills and I can throw all the catalogs and sale papers away on the advice of my Bank Statement's figures saying NO NO NO!!! Happy Holidays and a paper free New Year to you!

## Can you find the real Gloria in this picture?



*Our clinic staff dressed up as Gloria for Halloween this year!*

*continued from page 1*

## HINTS AND TIPS FOR LIVING WITH PD

# Surviving the Holidays

- If your relatives hesitate to pitch in and help, do not let them stay with you. Instead, give them hotel options in the area. Remember, you can always blame your doctor: "My doctor says I am not allowed to host a big crowd this year because of my PD."
- Do minimal cleaning, or hire someone to clean, before the event.
- Do NOT neglect your exercise and rest schedules. Tell people, "My doctor says I MUST exercise/rest everyday, so please excuse me for the next few hours."
- Avoid radical changes in your diet, fluid intake, and alcohol and caffeine consumption during the holidays.
- Consider catering or hosting/going 'Dutch treat' at a restaurant.

### **Gift ideas to give someone living with PD:**

- An Activity Card for The Parkinson's Institute exercise classes.
- Satin Sheets - makes getting in/out of bed smoother.
- Electric Toothbrush – makes caring for teeth easier.
- Wii FIT – to help PD patients stay active.
- Socks with rubber on the bottom – helps prevent slips when getting up at night.
- SUPER ball to bounce/catch while standing and walking.
- Trek Sticks for walking on uneven surfaces – hiking sticks are often better than a cane for support and balance.
- Massage Card for monthly massages – to loosen muscles.

### **Tips for planning ahead to avoid travel difficulties:**

- Always try to travel with a companion.



- Place the names of your doctor, insurance company, emergency contact, and medications in your wallet or purse.
- Carry identification stating that you have Parkinson's disease.
- Use a "fanny" pack or backpack so that you have both hands free to balance as you walk, especially if walking long distances.
- Pack snacks and carry a water bottle to take medications.
- Wear comfortable, loose-fitting clothing and good walking shoes.
- Request hotel rooms on the ground floor or near an elevator, or better yet, ask for a handicapped-accessible room. These rooms usually include grab bars in the shower and bathroom and have wider spaces between furniture for wheelchair access.
- Always have at least one day's dosage of medication in your pocket or purse.
- Carry all of your medications with you in case your luggage gets misplaced.
- Pack enough medications to last the entire trip.
- Do not rely on out-of-town, or especially out-of-the-country, pharmacies for refills.
- Before you leave, check with your doctor about using any over-the-counter drugs, such as those for motion sickness or diarrhea.
- Find out if your medications are "sun-sensitive" and plan accordingly.
- Always carry a list and schedule of medications.
- If possible, use a watch with an alarm or an alarm pillbox. If you are traveling with time changes it may be difficult for you to remember on your own.

## VOLUNTEERS NEEDED – *How you can help?*

The Parkinson's Institute is frequently in need of healthy volunteers for research studies. This group of individuals serves as "controls" and is essential to making comparisons with findings from Parkinson's patients. Most studies have to match patients to controls by gender and age, and because Parkinson's disease affects more men than women, the greatest need is for healthy men over the age of 50. However, this is also likely an age when men have a lot of other work and family commitments making it difficult to find the additional time to participate in research. As a result, researchers devote a great deal of time and resources to recruiting men in this age group.

Volunteering is one of the most generous gifts you can give a loved one affected by this disease. If you are interested in learning more about what you can do to help Parkinson's disease research, please contact Debbie McCullough, Clinical Research Assistant, at 408-542-5657 or [dmccullough@thepi.org](mailto:dmccullough@thepi.org). Thank you!

If you are interested in other opportunities to volunteer, including data entry, filing, event setup/cleanup, please contact Lauren Zachry, Development Associate, at 408-542-5636 or [lzachry@thepi.org](mailto:lzachry@thepi.org).

**DONATE TODAY –  
TO MAKE A  
DIFFERENCE  
FOR TOMORROW**



*"When I found out I had Parkinson's, I thought my life was over."*

*"Every day I live with a tremor, I fall, people stare, I forget things, and I never forget I have Parkinson's disease."*

*"Coming to The PI helped me realize that I am not alone. Participating in a clinical trial made me feel like I was striking back at the disease."*

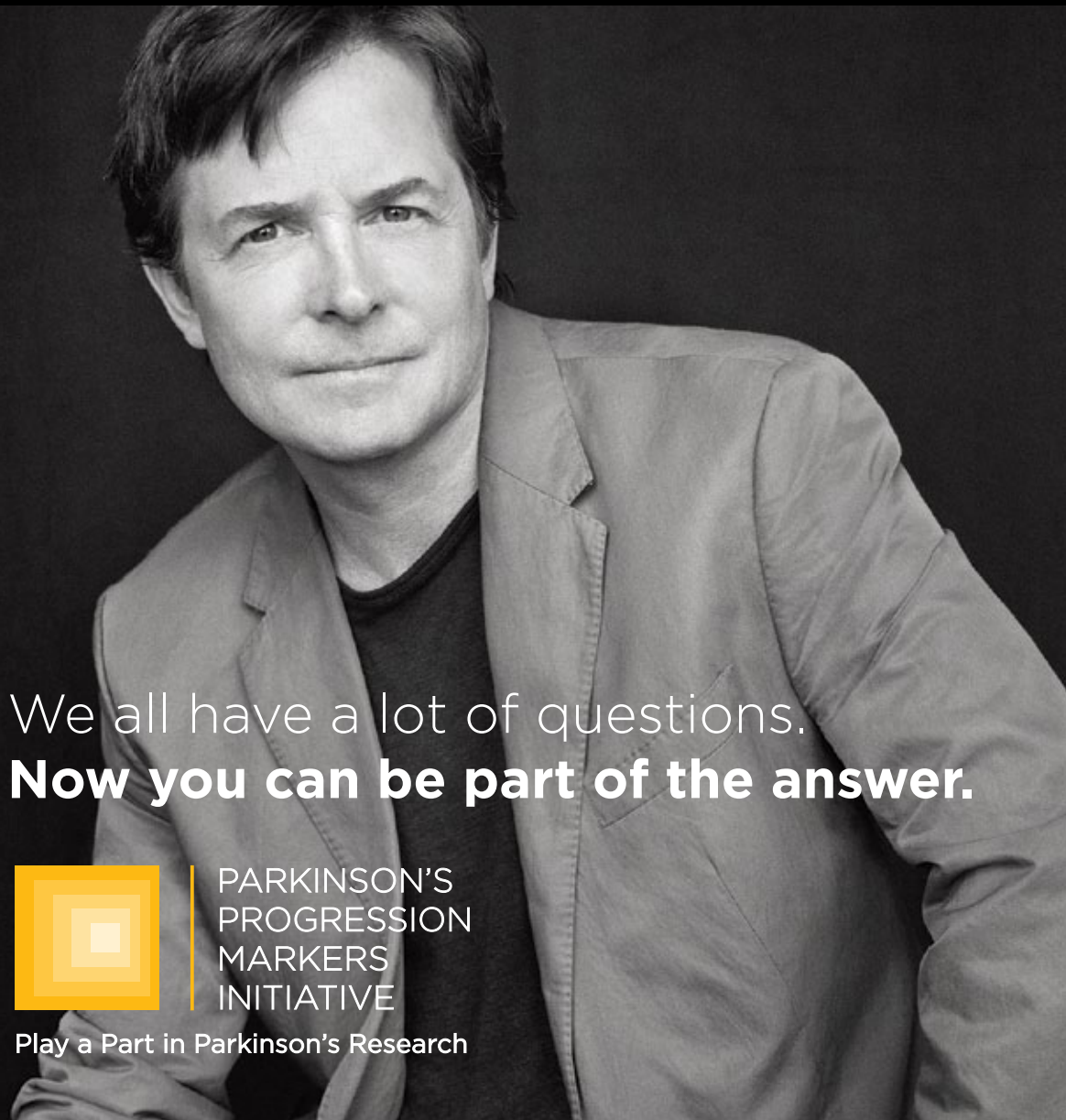
*"Our dance class is a support group – a little community where we can come together, laugh, cry and dance and know that we are never alone."*

*"When I was first diagnosed with Parkinson's disease, I spent 90% of my time anxious and upset. As a patient at The PI, I spend 90% of my time living my life and only 10% of my time managing and thinking about having PD."*

*Our patients are depending on support from you to help make a breakthrough. Do not let them down.*

### **You have the power to do something extraordinary.**

*Something that could change everything. The Parkinson's Progression Markers Initiative (PPMI) is an ambitious five-year study, the largest ever undertaken to pinpoint biological clues about the progression of Parkinson's disease. But it can't start without you. If you're newly diagnosed – or if you don't have Parkinson's disease and you're willing to participate in our study – please visit [www.michaeljfox.org/PPMI](http://www.michaeljfox.org/PPMI). Together, we can find the answers that can lead to new and better treatments for Parkinson's.*



We all have a lot of questions.  
**Now you can be part of the answer.**



**PARKINSON'S  
PROGRESSION  
MARKERS  
INITIATIVE**

**Play a Part in Parkinson's Research**

## RESISTANCE TRAINING

FRIDAYS  
2-3PM

\$10/CLASS  
AT THE PI



© Kenney Images Photography

*“I feel like even once a week is making a difference in my strength and muscle tone. I’ve noticed my upper body strength change since starting this.”*

– Ramon

*“In this class we are like the Three Musketeers – all for one, one for all.”*

– Carl

GET IN SHAPE FOR THE NEW YEAR

## Resistance Training Classes Offered

On Friday afternoons at The PI, a small group of dedicated PD patients gather around personal trainer Larry Hovland. Exercise is considered a cornerstone of Parkinson’s treatment, and participation in weight training and resistance class can be a crucial part of maintaining strength. Resistance training preserves muscle function and well-being, and maintains increased muscular endurance, thereby improving the ability of patients to continue daily activities. It also assists in stress reduction and mood elevation, can help prevent osteoporosis, and control high blood pressure

A few months ago, The PI staff recognized the need to expand our exercise program and added a resistance training class. In this class, walking and balance exercises help warm up the body for the bulk of the work out. They

begin with a warm-up and gentle stretching that focuses on all major muscle groups. Ankle weights are used to add resistance, thereby increasing stamina and strength while walking. Once they move to the weight lifting portion of the class they use weights (1, 2, and 5 lb. weights normally) with repetitions of 10 – 20 for each movement.

Larry’s interest in weight lifting began 30 years ago, and he has trained as a personal trainer for over 11 years. He has worked with everyone from the average Joe, to athletes, to the elderly. With his Parkinson’s class he notes, “Those with PD generally have more focus, and see how it will help their quality of life and give 100% in the class compared to other clients.”

***Before beginning a weight training, or other exercise program, consult your doctor.***

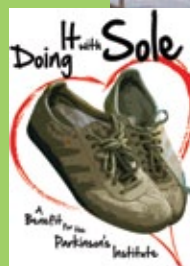
## PLANNED GIVING

You can help end Parkinson’s disease and protect future generations with a planned future gift. Planning your estate to include The PI can be comforting for you and your family. There are many ways to do so — bequests, charitable remainder trusts, charitable lead trusts and others — that may provide you with tax deductible savings now and in the future. We’d be glad to help. Contact Jonathan Friedman at [jfriedman@thepi.org](mailto:jfriedman@thepi.org) or 408-542-5606.

DOING IT WITH SOLE

## A Family Makes a Run Against PD

Congratulations to the *Doing it With Sole* Team on completing the Nike Women’s Half Marathon! Running in honor of their husband/father/uncle/brother-in-law, Carl, the team raised nearly \$10,000 in support of The Parkinson’s Institute. The PI Board of Directors and staff would like to thank them for running to support our efforts to cure PD.



## Diamonds in the Rough



Boots Brounstein, Dr. Langston, Charlie Trotter, and his wife, Rochelle Smith.

Many thanks to Mrs. Boots Brounstein and her committee, who combined the culinary talents of Charlie Trotter, with the musical

accompaniments of Mary Jensen and Frank Martin, to create a fabulous evening at the 8th Annual Diamonds in the Rough dinner. Hosted at Diamond Creek Vineyards, the guests enjoyed a magnificent sunset followed by exquisite wine and such delights as terrine of rabbit and ravioli of pig's tail. Over the past eight years, this annual event has raised over \$1.5 million for The PI in memory of Mrs. Brounstein's late husband, Al. She has worked tirelessly and generously to help The Parkinson's Institute remain a leader in the search for a cure for PD. At the event, Dr. Langston announced that the two fountains in front of our building will be dedicated and named in their honor, to memorialize the contributions Boots and Al have made to PD research and treatment.

## Danville Concours d'Elegance



The PI would like to thank the Danville d'Elegance Foundation and their planning committee for dedicating their time and efforts to raise money for Parkinson's disease research. Their two-day event began with *An Evening at The Blackhawk Automotive Museum*, which included dinner amongst the museum's impressive car collection, a lively auction and a host of speeches honoring racing enthusiast, David Love. This year's Concours d'Elegance event featured a DeLorean (provided by Oliver & Terry Holler) outfitted as though it was straight out of the "Back To The Future" movies. We would like to extend our gratitude to the entire planning committee for continuing to raise awareness around Parkinson's disease research and treatments, and for hosting such a spectacular event for the sixth consecutive year.



Jonathan Friedman, Director of Development at The PI, in the DeLorean, riding Back to the Future!



## KAY HANSEN NOSLER

July 16, 1945 –  
November 5, 2010

*A beloved member of The Parkinson's Institute community, Kay Nosler, passed away on November 5, 2010. Kay is survived by her husband Peter (Vice-Chairman of the Board of The Parkinson's Institute), their son Zander, and their five year old grandson, Ryden.*

*She will be remembered for her spirit and determination that left folks knowing what she valued, while never judging those around her. Her circle of loving friends is a testimony to her gentle nature, always filtering her determination and strongly held set of values.*

*In the early 1990's, Kay began making quilts and produced close to 40. She earned a reputation as a master quilt maker, and quilt making was a passion of hers. She inspired many, especially those of us at The Parkinson's Institute. She will be greatly missed.*

MISSED ONE OF OUR TALKS?

**WATCH THE VIDEOS NOW!**

Recently uploaded videos include:

- **BIOMARKERS AND CLINICAL TRIALS**
- **NOCTURNAL ISSUES OF PARKINSON'S DISEASE**
- **THE LATEST IN PD RESEARCH**
- **STEM CELL AWARENESS DAY**
- **HINTS AND TIPS FOR LIVING WITH PD**

[www.thepi.org/videos](http://www.thepi.org/videos)

## Stem Cell Awareness Day

For the second year, The PI hosted Stem Cell Awareness day. Held on October 6th, the event combined the efforts of the California Institute for Regenerative Medicine (CIRM) with the genetics work done here at The Parkinson's Institute. Speakers included Christopher Thomas Scott, Director, Stanford Program on Stem Cells in Society, Center for Biomedical Ethics; Tzvia Abramson, Ph.D., Associate Professor, Department of Biological Sciences, San Jose State University; Berta Strulovici, Ph.D., Chief Technology Officer, iPierian; and Birgitt Schuele, M.D., Clinical Molecular Geneticist, The Parkinson's Institute. The event highlighted current topics in stem cell research including the ethical and legislative issues. For more information, please visit our website to see speaker bios, download handouts and watch the video.

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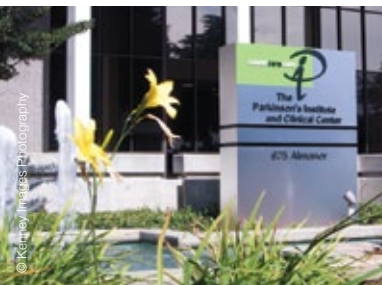


# The Parkinson's Institute and Clinical Center

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The Parkinson's Institute and Clinical Center

**Myspace:** user—theparkinsonsinstitute

**Twitter:** PDFighter

### OFFICE HOURS:

M – F 8:30am –5:30pm  
[www.thepi.org](http://www.thepi.org)

## Classes at The PI

Gait & Balance Class • LSVT Graduate Class  
PD Choir • PD DANCE: Poetry in Motion  
Weight Training for PD • Resistance Training  
Stress Management for Advanced PD

CHECK WEBSITE FOR DAYS AND TIMES

[WWW.THEPI.ORG](http://WWW.THEPI.ORG)

## UPCOMING EVENTS 2011

**FEBRUARY 16, 2011**  
EXERCISE AND HEART HEALTH FOR PD

**MARCH 3, 2011**  
NEWLY DIAGNOSED SEMINAR

**APRIL**  
NATIONAL PARKINSON'S  
AWARENESS MONTH

**APRIL TBD**  
CAREGIVERS AND PD

### RESOURCES FOR THOSE LIVING WITH PD

[WWW.PPSG.ORG](http://WWW.PPSG.ORG)

PARKINSON'S PATIENTS  
SUPPORT GROUPS

[WWW.MICHAELJFOX.ORG](http://WWW.MICHAELJFOX.ORG)

MICHAEL J. FOX FOUNDATION FOR  
PARKINSON'S RESEARCH

[WWW.CARING.COM](http://WWW.CARING.COM)

HELPING YOU HELP YOUR PARENTS

[WWW.PARKINSON.ORG](http://WWW.PARKINSON.ORG)

NATIONAL PARKINSON  
FOUNDATION

[WWW.PDF.ORG](http://WWW.PDF.ORG)

PARKINSON'S DISEASE FOUNDATION

[WWW.PDTRIALS.ORG](http://WWW.PDTRIALS.ORG)

PARKINSON'S CLINICAL TRIALS

[WWW.APDAPARKINSON.ORG](http://WWW.APDAPARKINSON.ORG)

AMERICAN PARKINSON'S DISEASE  
ASSOCIATION

[WWW.PARKINSONSACTION.ORG](http://WWW.PARKINSONSACTION.ORG)

PARKINSON'S ACTION NETWORK

[WWW.COASILICONVALLEY.COM](http://WWW.COASILICONVALLEY.COM)

COUNCIL ON AGING SILICON VALLEY

[WWW.NLM.NIH.GOV/  
MEDLINEPLUS/PARKINSONS-  
DISEASE.HTML](http://WWW.NLM.NIH.GOV/MEDLINEPLUS/PARKINSONS-DISEASE.HTML)

MEDLINE PLUS

