



# causecarecure

SUMMER 2010

## IN THIS ISSUE

- 1 Solvents & PD
- 1 A Good Night's Sleep
- 2 Staff Letter
- 3 Clinical Trial and Study Info
- 5 Genetic Research
- 6 The PI Dance Program
- 7 Community Gives Back
- 7 Patient Highlight
- 7 Crumbs from the Cookie Jar
- 8 Upcoming Events

## INDUSTRIAL SOLVENT LINKED TO INCREASED RISK OF PARKINSON'S DISEASE

# The PI Researchers Find More Potential Causes of Parkinson's



Results of a study by Samuel Goldman, M.D., MPH (Associate Professor at The Parkinson's Institute) and his colleagues in our Clinical Research Department confirm that workers exposed to the industrial solvent trichloroethylene (TCE) may be at a significantly higher risk

of developing Parkinson's disease. Dr. Goldman presented these findings at the recent American Academy of Neurology meeting in Toronto. TCE has been used since the 1920's and the most common occupational exposures are degreasing fabricated metal parts, cleaning computer circuitry and in the dry-cleaning and textile industries. Household exposures include decaffeinated coffee (until 1977), typewriter correction fluids, adhesives, paints and paint strippers, spot removers and carpet cleaners.

*continued on page 3*

## SLEEP AND PARKINSON'S DISEASE

# Tips for a Good Night's Sleep

by *Melanie M. Brandabur, MD*  
Clinic Director, The Parkinson's Institute

Most patients with Parkinson's disease will have problems with sleep at some point in their illness. The causes of sleep disturbances in PD are many, varied, and often overlap. It is important to diagnose and treat these issues because poor sleep at night is a common contributor to poor motor function during the day, as well as other problems, such as excessive daytime sleepiness.



Unfortunately, it is often the case that a non-specific complaint of difficulty sleeping results in a prescription for a sleeping pill instead of an examination of what the specific sleep difficulties are. The patient and family members can help by making careful observations about issues pertaining to sleep, thus assisting the doctor in making more specific and useful suggestions.

*continued on page 5*





Jonathan Friedman  
Director of Development

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# Letter From Our Staff

As a new feature of our newsletter, various staff members will be writing about the work they do, thoughts about Parkinson's disease, and the future of PD on a personal level. This is the first of such letters. We hope to give you unique insights into The Institute and let you know more about us. The first of these letters is from our Development Director, Jonathan Friedman

Dear Friends,

This month marks my first year anniversary at the Parkinson's Institute. I joined the spectacular people here because Parkinson's disease has affected my family. My brother, Joel, has Parkinson's disease; Dan, my other brother, is caring for his wife, who suffers from Parkinson's; my mom had Parkinson's, and several close friends have Parkinson's. As a development professional, I see this job as one in which I can make a significant difference for a cause that is personally meaningful. I share this passion with the entire staff here.

I find it inspiring to work here at The PI. Every day I see patients and caregivers who are struggling with the disease, and who fight hard – availing themselves of the tremendous resources we have here. As all of you know, The PI has the best doctors, health care professionals, exercise programs, speech therapies, an abundance of clinical trials, and, of course, the most welcoming receptionist. I am also inspired by our researchers. Some, like Dr. Caroline Tanner, have worked here for many

years. Others, like Dr. Jeremy Nichols, have just begun, but are already making substantial contributions. They are doggedly pursuing the ultimate goal of finding a cure.

I believe a cure will be found, but not without financial support, which makes my job both rewarding and challenging. The combined effects of the downturn in the economy, reduced government funding for research, inadequate payments from Medicare and private insurance for patient services, and fewer individual and foundation donations, have created financial challenges.

Many of you who are reading this letter are also affected by Parkinson's, and many of you have benefited directly, or indirectly from the work we do. Please take a moment to reflect about this. How has your life been impacted by The Parkinson's Institute? Included in this newsletter is an envelope which you can use to send in a contribution, or you can donate on-line through our website.

This is the time to dig deep and help me and our entire staff make a positive difference.

Best Regards,

Jonathan Friedman  
Director of Development



# cause

continued from page 1

## Solvents and PI

“This is the first time a population-based study has confirmed case reports that exposure to TCE may increase a person’s risk of developing Parkinson’s disease,” said study author Dr. Goldman. “TCE is a popular industrial solvent that is still widely used to clean grease off metal parts.”



worked in occupations such as dry cleaners, machinists, mechanics or electricians.

Although TCE exposure was more common among twins with PD, this study had several limitations including its relatively small size and imprecise exposure estimates. These results must be replicated in large populations with well-characterized exposures before we can conclude that TCE causes PD.

Even without replication, however, this study presents major public health implications, because TCE is still widely used in industry and is a common contaminant in air and water. In addition, other similar solvents should also be investigated as potential environmental causes of PD. Future research should also study the combined effects of genetics and solvent exposure in order to identify persons who may be more susceptible to solvent toxicity.

Study supported by: NINDS U10-NS31321, R01-NS40467; The Valley Foundation; James and Sharron Clark Family Fund



Dr. Samuel Goldman

For the study, researchers obtained job histories from 99 pairs of twins in which only one of the twins had Parkinson’s disease. All of the twins were men identified from the World War II-Veterans Twins

Cohort study. Scientists used twins in the study because they are genetically identical, or very similar, and provide an ideal population for evaluating environmental risk factors.

The study found that twins who were exposed to TCE were five and a half times more likely to have Parkinson’s disease than their unexposed twin. Those who were exposed to TCE had

MISSED ONE OF OUR TALKS? WATCH THE VIDEOS NOW!

Recently uploaded videos include:

**BIOMARKERS AND CLINICAL TRIALS IN PARKINSON’S DISEASE RESEARCH** The Michael J. Fox Foundation and The Parkinson’s Institute

**NOCTURNAL ISSUES OF PARKINSON’S DISEASE**

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

Sally Mak, PhD Staff Scientist



## 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)

## PARKINSON’S PROGRESSION MARKERS INITIATIVE (PPMI)

The goal of the PPMI study is to identify one or more biomarkers of Parkinson’s disease. The discovery of a biomarker of Parkinson’s disease is critical to the development of new and better treatments for PD, particularly treatments that could slow or stop the progression of the disease, something no currently available treatment can do.

*PPMI requires the participation of 400 Parkinson’s patients who are newly diagnosed and are not currently taking standard PD medications, and 200 individuals who do not have PD. Participants must be at least 30 years of age. They will be enrolled at about 18 Parkinson’s disease centers — 14 across the United States and 4 in Europe — over approximately two years.*

To learn more, contact Linda Rees, (408) 542-5664 or [lrees@thepi.org](mailto:lrees@thepi.org).

## GRANT TO FUND PARKINSON'S CLINIC AND OUTREACH

On April 27, 2010, William Upson secured a \$5,000 grant from The Million Dollar Round Table Foundation (MDRT) on behalf of The Parkinson's Institute and Clinical Center.

Mr. Upson, of Strategic Asset Management Group, is an active supporter of The PI and nominated and endorsed the grant application. The check was presented at "The Nocturnal Issues and Parkinson's Disease Seminar."

The Parkinson's Institute would like to thank MDRT and our nominating sponsor, Mr. Upson, for providing funds that will help increase our ability to reach out to patients and educate the community about Parkinson's disease.

*Clinic Director, Melanie M. Brandabur, M.D. and MDRT sponsor, William Upson of Strategic Asset Management Group.*



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## Sleeping with PD

There are some interventions that may be helpful with most sleep issues in PD. This includes eliminating caffeine in the afternoon and evening, having set hours for waking and sleeping, limiting naps to no more than 20-30 minutes, and spending some time outdoors in natural sunlight every day. These principles are called "good sleep hygiene."

In some cases, your primary care doctor or neurologist may recommend consultation with a doctor specializing in sleep medicine for more specific diagnosis and treatment of sleep difficulties. This may involve a polysomnogram or sleep study which involves sleeping while monitored so that changes in heart rate, movements and oxygen saturation can be measured.

### **Wearing off of medications:**

One of the most common problems that occurs with PD is wearing off of anti-parkinsonian medications. In early PD, most patients still have a fairly good supply of dopaminergic neurons within the brain and medication is typically geared towards the daytime hours when they need additional dopaminergic medications to improve function. Since PD is progressive, the number of dopamine neurons continues to diminish over time and patients may notice a return of symptoms, often in the evening and nighttime. This may result in difficulty getting ready for bed or getting comfortable for sleep. If the medication effects wear off during the night, the patient may be unable to turn over in bed or get up safely to use the bathroom. Profuse sweating is another symptom that can occur when the medication wears off during the night.

Most of these symptoms are treated fairly easily by medication adjustments, such as additional levodopa or dopamine agonist during the evening hours and/or at bedtime. Some non-medication adaptations that may help include installing a bedrail or floor-to-ceiling pole to aid mobility while turning over or getting in and out of bed. Using satin sheets or nightwear to make movement easier once in bed may also be helpful.

### **REM Sleep Behavior Disorder (RSBD)**

Rapid Eye Movement, or REM sleep is the phase of sleep during which dreams occur. Normally,

people are paralyzed during this phase, but in RSBD, people appear to act out their dreams; sometimes just talking, but often thrashing around, yelling out or even attacking whomever is nearby. This can result in bruises or even serious injury to the patient or sleeping partner. RSBD is quite common in PD and may precede motor symptoms by years or even decades. Symptoms may respond to small doses of clonazepam. However, like any sedating medication, this must be used cautiously to avoid falls or confusion during the night. In addition, patients with Obstructive Sleep Apnea should generally have this condition treated before sedation is used to avoid worsening the sleep apnea.

### **Obstructive Sleep Apnea (OSA):**

OSA is a fairly common occurrence in people with PD. In this condition, airflow ceases periodically, often in association with snoring. The episodes of apnea are often accompanied by decreased levels of oxygen in the blood and other changes in metabolism. This can result in high blood pressure and increased risk of stroke and heart disease. Sometimes, the treatment is as simple as adjusting sleep position. Often, however, the treatment consists of wearing a facemask or nasal device connected to a small machine that applies positive pressure to keep the airways open and facilitate airflow. This is called a CPAP machine. It may take some adjustments to get used to wearing the device during sleep, but the decreased risk factors and improved restful sleep is worth the effort and discomfort.

### **Early AM waking**

Many patients are able to fall asleep without difficulty but awaken frequently during the night or wake up early in the morning and are unable to go back to sleep. The patient may describe worrying or ruminating over concerns in his or her life. This often results from anxiety or even depression, perhaps due to changes in serotonin and norepinephrine levels in the brain in PD. For this reason, treatment of mood with a selective serotonin reuptake inhibitor (SSRI) may be useful.

There are other sleep difficulties that occur in PD. Careful observation of the circumstances surrounding sleep difficulty will enable your physician to diagnose and treat the problem, often in a more effective manner than by simply prescribing a sleeping pill.

## GENETIC LINKS TO PARKINSON'S DISEASE

# Better Understanding the Genetic Makeup of PD Patients

The study of genetics and PD has been rapidly progressing in recent years, as seen with the creation of the 23andMe Parkinson's Research Initiative. Launched in March 2009, this initiative is a way for individuals to better understand a portion of their genetic code, allowing for the exploration of disease risk and information on two highly predictive mutations in the LRRK2 gene.

This large scale study has independently identified many of the same genetics markers previously found by Parkinson's researchers. For example, 23andMe found that a particular gene variation reduces the odds of Parkinson's

by 21%, very much in line with the published figure of 23%. Combining genetics with patient surveys, 23andMe research has verified that carriers of the LRRK2 gene who have PD show fewer symptoms than other patients when adjusted for duration of the disease, age of onset, and sex (for more specific information please visit <http://spittoon.23andme.com>, January 26, 2010).

If you would like more information on this 23andMe Parkinson's research project please email [pd-help@23andme.com](mailto:pd-help@23andme.com), visit the website [www.23andme.com/pd](http://www.23andme.com/pd) or call 650-963-8900.

## UPCOMING GENETIC RESEARCH STUDIES

# Next Generation Sequencing in Familial Parkinson's Disease

Working with Dr. Curt Scharfe of the Stanford Genome Technology Center, our Clinical Molecular Geneticist, Dr. Birgitt Schüle is further exploring the connection between genetics and Parkinson's disease. PD affects an estimated 1.3 million Americans, but there is currently no cure for PD or effective way to slow disease progression, and all the causes of the disease remain unknown.

Genetic contribution to sporadic PD has been found in association studies and variants in the SNCA gene and GBA gene have been replicated consistently. Furthermore, mutations in at least five disease genes (SNCA, PARK2, PINK1, PARK7, and LRRK2) were identified in traditional studies. However, overall causal DNA variants have been detected in only 5%-10% of PD cases, which leaves probably the vast majority of genetic contribution to PD still unexplained.

The overall goal of this project is to conduct a large scale gene sequence analysis in an effort to discover novel genes involved in the cause

and development of PD. This study is based on the emerging hypothesis that rare DNA variants are more likely to be functional and causal than common variants in complex diseases. In this study, we investigate over 500 genes simultaneously with novel high-throughput techniques. We use DNA (genetic material) from blood or saliva of individuals and study the genetic variability in Parkinson's patients compared to unaffected and affected relatives. The comparison to healthy relatives is a crucial component of the study to rule out common genetic factors that do not contribute to the disease.

For more information about genetics projects at The PI, please contact Dr. Birgit Schüle ([bschuele@thepi.org](mailto:bschuele@thepi.org) or 408-734-2800) for more information.



Malini Mangipuram, Intern

## VALIDATING INTERNET RESEARCH

23andMe is moving beyond genetics by partnering with The PI in studying online data collecting methods. With the support of the Michael J. Fox Foundation, The PI founder, Dr. J. William Langston and his colleagues at The PI and 23andMe are conducting a research study designed to validate the use of the Internet to study Parkinson's disease and related movement disorders. Valid internet data collection methods will enable researchers to develop new approaches to medical research that could overcome some of the obstacles to study participation.



© Kenney Images Photography



Damara Vita Ganley (center)

© Kenney Images Photography

***“The music gets going and you’re feeling lively and for a few moments, I forget that I even have PD.”***



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INSTITUTE AND  
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## Parkinson’s Patients Dance to a New Beat

Exercise is vital for Parkinson’s disease patients. Many patients and doctors tend to overlook the significance of movement for both the emotional and physical health of those suffering from PD. At The Parkinson’s Institute we believe in multidisciplinary care and our doctors encourage exercise as a part of PD treatment – *please consult with your doctor before beginning any new exercise program.*

One of the classes offered here at The PI is Dance for PD. This program began as a partnership between the Brooklyn Parkinson Group (BPG) and the Mark Morris Dance Group. Professional dancers are trained to lead and create dance classes for people with Parkinson’s. As movement experts, it is fitting that professional dancers would be able to bring life and joy to those suffering from movement disorders. We are lucky to have one of these specially trained artists join us here, Damara Vita Ganley. Damara is a professional dancer with two San Francisco based dance companies, Project Bandaloop and Joe Goode Performance Group. Damara trained with the originators of Dance for PD, Mark Morris Dancers, David Leventhal and John Heginbotham, and BPG Executive Director Olie Westheimer. She has been offering Dance for PD classes at The PI for over a year now. Being full of passion and life, Damara brings a joy and freshness to dance that is contagious.

For many of the participants in Dance for PD, this class has become a family and an unofficial support group. A regular participant, Monica, commented that she began attending the class

out of curiosity and has found an extended family to play and dance with. These are the types of experiences that foster joy, happiness, and hope – all experiences that raise the spirits of Parkinson’s patients. Ramon said being in the class for just one hour allows him to “completely forget [he has] PD.”

Part of the emotional connection felt during this class is the incorporation of words with movement to help participants express themselves. This begins with introductions. Each person attaches a movement to their name, thereby expressing how they feel at that moment, and the class ends with a thank you and a smile to your neighbor. It is easy to see how emotional expression, partner dances and positive interaction among the participants can make them feel a part of a small community.

One of the biggest challenges faced by this class is a current lack of funding. “This is my favorite class to teach. It brings me so much joy and I am committed to continuing to offer these classes here at The PI. My goal is to develop a continuous program of weekly Dance for PD classes with live musical accompaniment so that beauty, grace, connectivity and meaning can be cultivated and shared while we build strength, coordination and balance,” says Damara. Current funding is limited and unless we find new sources of financial support this dance program may be dropped. If you would like to support the dance class, please call Jonathan Friedman at 408-542-5606 or email him at [jfriedman@thepi.org](mailto:jfriedman@thepi.org).



Dance for PD Class

© Kenney Images Photography

## High School Student Honors Grandfather

When her grandfather was diagnosed with PD in early 2009, high school student, Courtney Quinn knew she wanted to do something to help. During her senior year at Presentation High School, Courtney and fellow senior, Lindsay Vong worked tirelessly to raise awareness about PD and raised over \$2,000. They began the year with bake sales and pumpkin grams, all the while telling fellow students about the effects of PD and the importance of organizations such as The Parkinson's Institute. Their fundraising efforts culminated in a Dance-A-Thon, complete with a DJ and live dance instruction. "It was important that we teach our classmates about PD and have fun while doing so," said Courtney. "This process has been amazing because not only have I been able to help a great organization, but I have learned a lot about PD and how important research will be for Courtney's grandfather" said Lindsay. Both girls have truly inspired us here at The PI, and we would like to thank them and their families for all of the time and effort they put into partnering with us.



Lindsay Vong and Courtney Quinn

## Patient Hosts Fundraiser

In an effort to promote The Parkinson's Institute and our services, patient Eva Yarmo hosted a fundraising and informational event at her home in Berkeley. She courageously wrote a letter to her friends announcing her struggle with Parkinson's disease and encouraged them to come learn more about us. Guests heard about our newest studies in clinical research, including the report that there is an increased risk for PD in occupations involving industrial solvents, and Clinic Director, Dr. Melanie Brandabur spoke about clinic services while answering diagnostic questions about PD. The entire staff and Board of Directors would like to thank Eva for hosting such an amazing event and raising funds to help support Parkinson's disease research and treatment.

## CRUMBS FROM GLORIA'S COOKIE JAR

*As I filled my cookie jar this morning I kept thinking about the book I left open on the breakfast table. I was reading it avidly as I nibbled on my second slice of toast. It is really getting to the exciting part!! I am anxious to find out how it ends, but, also, almost dreading beginning the last chapter as I feel like I'll be losing some special friends because the characters have become so alive as I get more engrossed in the plot.*

*Which brings to mind one of my favorite sayings: "A good book on your shelf is a friend that turns its back on you, but always remains a friend."*

*See you all next month!!!  
Double "G"*

**"LIFE MAY NOT BE THE PARTY YOU HOPED FOR, BUT SINCE YOU'RE HERE YOU MIGHT AS WELL DANCE." –KAREN FISHBACK**

## A Patients Journey with PD

Such is the philosophy Karen Fishback carries with her. When she was diagnosed with Parkinson's ten years ago and could no longer play badminton or tennis, she went looking for an activity she could still do. She discovered the world of dance, but being able to continue exploring this new world had some stumbling blocks.

After several unsatisfactory visits to a variety of neurologists, who provided only vague answers to what was happening to her, a friend told her about The Parkinson's Institute.

"It was wonderful to find someone who actually understood what was going on,"

she says. She was immediately asked if she would like to participate in a clinical trial. "After feeling as if my life was over, it was great to be able to contribute something."

Three years and four clinical trials later, she went downhill rapidly and began taking medication. "After a few month I got almost everything back," she says. Seven years later, she is still going strong.

Through it all, she has stayed on the dance floor. She has taught line dancing and with her husband, participates in Swing, Two Step, Waltz, English Country, and a variety of other dances, even

attending a dance camp for a week every summer. She

has also published a book of local history, "Lakeside Legends, The First 125 Years" and stays active with backpacking, skiing, gardening and working around the family's Christmas tree farm.

"None of this would have been possible without The PI," she says. "The PI has been a Godsend. I don't know what I would do if it hadn't been there. It makes such a difference."



Jeff and Karen Fishback dancing at the Dickens Fair

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## Classes at The PI

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- PD Choir • pd DANCE: Poetry in Motion
- Weight Training for PD
- Stress Management for Advanced PD

CHECK WEBSITE FOR DAYS AND TIMES

**WWW.THEPI.ORG**

### RESOURCES FOR THOSE LIVING WITH PD

**WWW.PPSG.ORG**

PARKINSON'S PATIENTS  
SUPPORT GROUPS

**WWW.PDTRIALS.ORG**

PARKINSON'S CLINICAL TRIALS

**WWW.MICHAELJFOX.ORG**

MICHAEL J. FOX FOUNDATION FOR  
PARKINSON'S RESEARCH

**WWW.APDAPARKINSON.ORG**

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**WWW.NLM.NIH.GOV/  
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DISEASE.HTML**

MEDLINE PLUS

## UPCOMING EVENTS 2010

**JULY 14TH**

**NAVIGATING THE FINANCIAL AND LEGAL  
ISSUES OF PARKINSON'S CARE**

*From our ongoing Parkinson's Disease Education Series, this event focuses on financial planning, wills and trusts, medical insurance, and disability.*

**JULY 29TH OR SEPTEMBER 22ND**

**NEWLY DIAGNOSED SEMINAR**

*Have you been recently diagnosed with Parkinson's disease? Have your questions answered by our neurologists and learn about the basics of Parkinson's disease.*

**SEPTEMBER 18TH AND 19TH**

**DANVILLE CONCOURS D'ELEGANCE**

*Rare and magnificent vintage cars are proudly displayed, with wine tasting, racing car celebrities, and a major dinner event. In Danville, CA.*

**OCTOBER 2ND**

**DIAMONDS IN THE ROUGH FUNDRAISER**

*Once a year entertainment and celebrity chef dinner – this year is Charlie Trotter – at Diamond Creek Winery in Napa Valley hosted by Boots Brounstein.*

**IF YOU'D LIKE MORE INFORMATION,  
PLEASE CALL US AT 408-734-2800 OR  
GO TO WWW.THEPI.ORG**

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