

# Greater Fresno Parkinson's Support Group

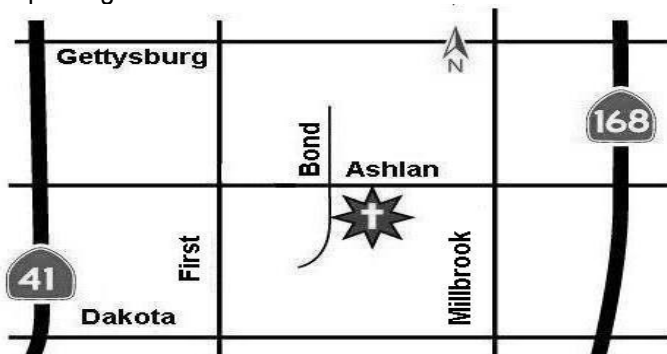
"Helping to optimize the quality of the lives of *People With Parkinson's* and their *Care Partners*."

Our Support Group meets the second Saturday of every month **except August**.

 Our Next Meeting is on 

**SATURDAY, SEPTEMBER 11, 2010**  
**10:00 a.m. – 12:00 p.m.**

At **THE BRIDGE EVANGELICAL FREE CHURCH** in Rooms 212-213 upstairs via elevator in the **Atrium** at **3438 E. Ashlan Ave., Fresno, CA 93726**, at the southeast corner of Ashlan & Bond between First & Millbrook. Enter the parking lot from Ashlan Ave.



## Word of the Month:

**Glutathione** [gloo'tethi'ōn] L, *gluten* + Gk, *theione, sulfur*: a tripeptide of glutamic acid, cysteine, and glycine whose deficiency is commonly associated with hemolytic anemia. It functions by taking up and giving off hydrogen. It transports amino acids across cell membranes and conjugates to drugs enabling excretion. Glutathione is produced by our bodies. Levels decrease with aging and from many diseases including Parkinson's disease. Glutathione is a potent antioxidant in the brain, and the loss of glutathione is one of the earliest reported changes in Parkinson's disease.

## Synopsis of the July 12, 2010 Meeting:

At our July 12th general meeting, Bruce Medlin emceed and invited members to attend a no-host lunch at Carrow's after the meeting.

We were then introduced to Dr. M. Nezami, a family practitioner in Fresno specializing in anti-aging medicine. He presented an approach to treatment of neurodegenerative disorders, including Parkinson's disease, multiple sclerosis, and dementia, which contrasts with established medical treatment for such illnesses. The focus of the treatment is on providing the body with antioxidants and other supplements to improve wellness generally. In response to a question from the floor, Dr. Nezami acknowledged that such treatment is not confirmed as effective by normal medical testing, nor is his treatment covered by any health insurance plan. (From information furnished after the meeting, the cost of such treatment is substantial.)

Some GFPSG members have reported feeling favorable about the results from this treatment, and others have come to a contrary view. Our organization's role is to give our community access to information from a wide range of sources so they can make their own best decisions on their medical care. In no case does GFPSG endorse particular practitioners.

Dr. Nezami provided websites regarding pesticides and other toxins which may be part of the cause of PD: [www.scorecard.org](http://www.scorecard.org), [www.pesticideinfo.org](http://www.pesticideinfo.org), [www.atsdr.cdc.gov](http://www.atsdr.cdc.gov), and [www.hazard.com/msds](http://www.hazard.com/msds).

## Resource of the Month:

[www.healthline.com/channel/parkinsons-disease.html](http://www.healthline.com/channel/parkinsons-disease.html)

A comprehensive website on Parkinson's disease with in-depth/informative links.

Please respect the *confidentiality* of personal medical information revealed to one another in our meetings. Always *check with your own doctor* before changing your medications or treatments based on what you read in this Newsletter or hear at our meetings from others, even medical experts, as Parkinson's disease is such a complex disease and our respective bodies react differently to the disease and to the medications and treatments prescribed to treat it.

## Getting to Know: PATRICIA JORN



Patricia Jorn was born in Fresno and has lived in the Valley all her life. She raised three children from her first marriage. Pat worked thirty years for a prominent building contractor as his executive assistant. In 1979, her second marriage was to Bill Jorn who became the love of her life. During Bill and Pat's life together, they both continued to work and also ran a successful quarter horse ranch where they resided in the foothills. Unfortunately, within just three years of her marriage to Bill, Pat was diagnosed with Early Onset Parkinson's disease. Her disease advanced rapidly.

Pat was active in research for her disease and has an extensive library on the subject. She soon found Dr. Markham with USC who was researching brain implants. Also during her internet searching, she found doctors who had performed this type of surgery in Belgium. However, the procedure was not approved by the FDA for the United States. As she continued her research, Pat found Dr. Richards in Oakland, who in turn referred her to a fellow neurosurgeon, Dr. Tamas in Olinda. Pat left a message with his assistant, and the very next day Pat received a telephone call from Dr. Tamas. Within a week, Pat and Bill met with the doctor to discuss brain implants.

Pat was tested and interviewed for the first FDA approved Deep Brain Stimulation/Subthalamic Nucleus surgery in the United States. Surgery was scheduled for November of 1997. The survival rate was expected to be 65%. The insurance company would not cover the costs of "experimental procedures," so the FDA paid \$127,000 while Patricia paid \$25,000 out of pocket. The procedure took 11 ½ hours and went well. The next day she was able to get up and walk without tremors or problems, continuing on her medications. Bill was by her side throughout the surgery and recovery. Pat managed well for the first five years after surgery, but over the next five years there was significant advancement in her PD while her general health continued to decline. When there was a thunderstorm in the foothills near their ranch, Pat could feel the lightning strikes like a shock hitting her body! Bill continued to be Pat's primary and faithful care partner until his untimely death in September of 2007 after which the family moved Pat from the ranch into an assisted living facility in Fresno. Two strokes and a broken shoulder have slowed her down, but she does the best she can, and focuses on the positive. She says there is always someone who is worse off than you are, and to do the best you can!

Eight months ago, Pat was told she would lose her ability to talk within a month, but she is still able to communicate well, if softly. In fact, the past six months have shown additional signs of improvement, and Pat has been able to move from an assisted living facility to an independent living apartment. "Charmayne," her loyal calico cat, protects Pat and growls if a stranger approaches or if Pat is having a health crisis. Every day Pat's care partner walks her out to the front porch for some fresh air and an opportunity to work on her gardening hobby and to take a stroll together down the path and back. Pat continues her medications under oversight by Dr. Calmes who also adjusts her DBS settings. Pat recommends that anyone who is eligible for DBS surgery should fight to get it and continue to fight their disease one day at a time. Pat is a fighter after 25 years with PD. She says she may have Parkinson's, but Parkinson's does not have her!

### OFFICERS

#### Co-Leaders/Emcees:

Russell Templeton  
Doug Jackson  
Bruce Medlin

#### Treasurer

Barbara Burmeister

#### Membership Committee:

Sue & Doug Jackson  
Faye & Jack Smith

#### Care Partners Group Leader:

Anne Guenther

#### Librarian:

(seeking volunteer)

#### Newsletter Editor:

Ellen Jablonski

### STEERING COMMITTEE

Bill & Barbara Burmeister  
Anne Guenther  
Ellen Jablonski  
Doug & Sue Jackson  
Riley and Linda Jones  
Bill and Kathy Larkin  
Jocelyn Lock  
Bruce Medlin  
Jack & Faye Smith  
Russell & Jan Templeton  
Martin and Marianne Weil

### WEBMASTER

Frédéric "Fredo" Martin  
Workingarts Marketing, Inc.™

### PEER COUNSELORS FOR OUR CARE PARTNERS

Anne Guenther (559) 322-7076  
Sue Jackson (559) 434-7928

Or online:

Caring From a Distance:  
[www.cfad.org](http://www.cfad.org)

Family Caregiver Alliance:  
[www.caregiver.org](http://www.caregiver.org)

Natl. Family Caregivers Assoc.:  
[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

Well Spouse Association:  
[www.wellspouse.org](http://www.wellspouse.org)

FOR MORE INFORMATION,  
TO UPDATE OUR MAILING LIST,  
OR TO SUBMIT MATERIALS OR  
SUGGESTIONS, CONTACT:

#### Ellen Jablonski

(559) 298-4080

Ellen4curePD@att.net or

#### Barbara Burmeister

(559) 322-8076

[bburmeister@sierratel.com](mailto:bburmeister@sierratel.com)

106 W. Paul Avenue  
Clovis, CA 93612

[www.FresnoParkinsons.org](http://www.FresnoParkinsons.org)

**(559) 593-9953**

## Treasurer's Report by Barbara Burmeister:

### Greater Fresno Parkinson's Support Group (GFPSG) Checking Account Report:

The June 24 - July 26, 2010, Wells Fargo Bank Statement shows a beginning balance of \$1,083.39. Debited from the account during this period were three checks totaling \$167.98 for newsletter-related and meeting refreshment expenses. Deposited to the account was \$192.00 in donations from the July Support Group meeting. The current ending balance in the checking account is \$1,107.41. A \$250.00 check to *The Bridge* in appreciation for allowing our Support Group to utilize their facilities without charge is still outstanding. Monies donated directly to our Support Group are not tax deductible; however, they do help cover the cost of newsletter, refreshment, and operating expenses. Thank you for your continued generous support.

**Fresno Regional Foundation Account Report:** There was one donation in the amount of \$50.00 made to the GFPSG fund held at the *Fresno Regional Foundation* in July. The current balance in our *Foundation* account is \$3,323.59. Donations or gifts to our Support Group through the *Fresno Regional Foundation* are tax deductible. Donations can be made by check, Visa or MasterCard, or online. Make your check out to the *Fresno Regional Foundation* and specify that the donation or gift is for the *Greater Fresno Parkinson's Support Group Fund*. The mailing address for the *Fresno Regional Foundation* is: 5250 N. Palm Avenue, Suite 424, Fresno, CA 93704. For additional information, you can call them directly at (559) 226-5600 or visit their website at [www.fresnoregfoundation.org](http://www.fresnoregfoundation.org).

### In Memoriam:



Dexter Aquino  
Andy Balakian  
Irwin Smith



### Chuckles of the Month:

Stupidity is not a handicap. Park elsewhere!  
I used to have a handle on life, but it broke.  
Ever stop to think, and forget to start again?

### Ibuprofen May Lower the Risk of Developing Parkinson's Disease: *HealthDay News, by Reporter Ellin Holohan, Feb. 17, 2010*

Regular use of ibuprofen, a common anti-inflammatory drug, significantly lowers the risk for developing Parkinson's disease, Harvard researchers report. People who took three or more tablets a week showed a 40 percent lower risk than those who didn't take the common pain reliever, their study found. Study author Dr. Xiang Gao, an instructor and epidemiologist at Harvard Medical School and Brigham and Women's Hospital in Boston, said the findings are important for anyone at increased risk for Parkinson's because most people with the disease eventually become severely disabled. "There is thus a need for better preventive interventions," Gao said. "In this context, our findings regarding the potential neuroprotective effect of ibuprofen, one of the most commonly used analgesics, on Parkinson's disease may have important public health and clinical implications." Gao said that though the drug levodopa is the current standard treatment for Parkinson's, much more is needed. He is scheduled to present the findings in Toronto at the annual meeting of the American Academy of Neurology in April. The findings came from an analysis of data on 136,474 people who did not have Parkinson's at the start of the study. In a six-year span, 293 were diagnosed with the disease. Those who took the largest doses of ibuprofen were less likely to have developed Parkinson's than were those who took smaller amounts of the drug, the study found. No other pain reliever was found to lower the risk for Parkinson's. Dr. Michele Tagliati, an associate professor of neurology and director of the Parkinson's Disease Center at the Mount Sinai School of Medicine in New York City, described the results as somewhat surprising and said they emphasized the need for further study. "It's intriguing [that the finding applied to] just ibuprofen and not aspirin or acetaminophen or other commonly prescribed medications for inflammation because it implies something more specific to ibuprofen that should be investigated," Tagliati said. "So it narrows the focus to a subgroup of [anti-inflammatory drugs]." Tagliati called the study "eye-opening." Parkinson's is not considered an inflammatory disease, he said, adding: "We might be missing something. There is more work to be done." But in the meantime, Tagliati said, he would "definitely discuss ibuprofen use" with his patients because, if it works to protect against the disease, it could very well benefit those who already have it. He cautioned that persistent use of ibuprofen can lead to gastritis, or inflammation of the stomach lining, but said that, in comparison, "there is very little to lose when measuring its side effects against the effects of Parkinson's," which can include loss of balance, stiffness, hallucinations and dementia.

**Words of the Month:** *Soporific* (səp' ə rif' ik, sō' pə rif ik,) *adj.*: causing or tending to cause sleep; also *soporiferous* of or characterized by sleep or sleepiness; *noun*: something, as a drug, that causes sleep.

## Stem Cell Groups Warn of “Rogue” Clinics, *Northwest Parkinson’s Foundation, 2010*

Patients considering going overseas for stem cell therapies should ask some serious questions before they shell out thousands of dollars for what could be an unproven therapy, the International Society for Stem Cell Research (“ISSCR”) warns. The ISSCR released a list of "Top Ten Things to Know About Stem Cell Treatments" as part of a report that lists how patients can evaluate stem cell therapy clinics. The society said it felt compelled to issue the report and to launch a website called "A Closer Look at Stem Cell Treatments" because of a growing number of aggressive marketing campaigns on the Internet and elsewhere, promoting stem cell treatments.

Canada's Stem Cell Network (“CSCN”) said it was delighted with the report, noting that many overseas clinics are making claims of cures or treatments without any scientific evidence. "The false claims and unscrupulous methods through which some clinics attract patients has quickly become one of the most important concerns facing the field today," Drew Lyall, the CSCN’s director and one of the authors of the report said in a news release.

Dr. Irving Weissman, President of the ISSCR, explained that while stem cells "hold tremendous promise" for the treatment of many diseases, the research on whether such treatments are either effective or safe for most conditions is simply not there yet. "There are organizations out there that are preying on patients' hopes, offering stem cell treatments – often for large sums of money – for conditions where the current science simply does not support its benefit or safety," Weissman said in a statement. "We feel it is an obligation of the ISSCR to both a) alert patients and care partners about clinics and other entities that are selling unproven ‘stem cell’ therapies, and b) help shepherd real stem cell advances from discovery to successful patient treatments as rapidly as possible."

Among the ISSCR's "Top Ten Things to Know About Stem Cell Treatment": If a clinic says it can treat a variety of ailments using a single type of stem cell, that's "a major warning sign." Clinics that say they can use stem cells from one part of the body to treat another part are also suspicious. Patient testimonials are no substitute for rigorous scientific study. Be wary of those that advertise their results primarily through patient success stories.

The ISSCR notes that currently there are only a small number of conditions that have been shown to benefit from stem cell therapy. These are mostly blood diseases, as well as corneal conditions and skin grafts. Yet many clinics are promoting cures for everything from cancer to cerebral palsy to Parkinson's disease.

Joyce Gordon, president and CEO of the Parkinson Society Canada, welcomed the new website, noting that her group's offices regularly receive inquiries from patients about the usefulness of stem cells in treating Parkinson's. "Patients want to know whether the treatment offered by overseas clinics is effective and worth the cost. Since Parkinson's is one of the diseases unsupported by clinical evidence for these treatments, the new resource will provide more critical information so people can evaluate the claims by overseas clinics," she said in a statement.

The report recommends that each clinic be evaluated on whether it's been approved by a research ethics board in its jurisdiction, and whether it's been approved by an internationally recognized national oversight body.

The ISSCR's website, [www.isscr.org](http://www.isscr.org), includes a list of questions that patients should ask their doctors about stem cell treatments and videos from experts explaining why true stem cell therapies take so long to develop. As well, patients can ask the ISSCR to offer its review of particular clinics.

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**NOTE: There will be no GFPSG meeting in August.**