

Greater Fresno Parkinson's Support Group

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

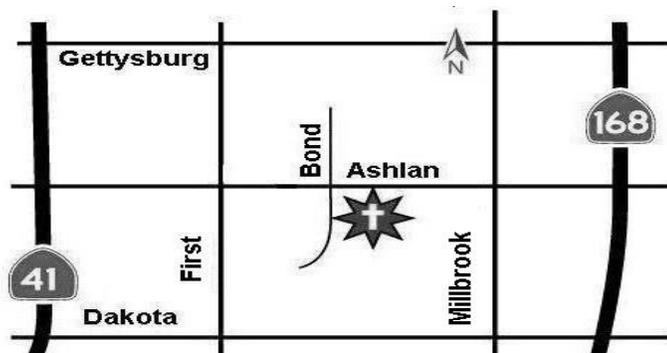
HAPPY MOTHER'S DAY!!!

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

 Our Next Meeting is on 

SATURDAY, MAY 8, 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.



Chuckle of the Month

JAMES (age 4) was listening to a Bible story. His dad read: "The man named Lot was warned to take his wife and flee out of the city, but his wife looked back and was turned to salt." Concerned, young James asked: "What happened to the flea?"

Submitted by Jan Templeton

OUR PROGRAM:

Interest has been expressed in having a relatively comprehensive presentation on the types of medical equipment available to assist People With Parkinson's ("PWP") and their Care Partners at various stages in getting around. These might include a cane or walking stick, shower equipment, walkers, wheelchairs (motorized or not), scooters, etc. After all, Parkinson's disease is described as a "movement disorder" and maintaining our mobility is a primary goal.

Based on this, we contacted one of the leading suppliers of such articles in the valley, *The Bone Store*. They have agreed to bring a wide variety of items to our meeting and to provide demonstrations, discussions of advantages and disadvantages, and financial information including insurance coverage on the equipment.

Of course, there will be ample opportunity for questions and answers, and for people to share their own experience. Having a full picture of what is available will be helpful for planning for the future as well as meeting immediate needs.

The Bone Store will also be providing discount vouchers for all attending the meeting.

The Bone Store is located at 343 E. Shaw Avenue, Fresno, CA 93710, phone: (559) 226-7500

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: PAT NEEL and CAROL OTT



Carol Ott and Pat Neel

Pat Neel is new to the Fresno/Clovis area, having lived her entire life in the New England states. She was born in Hamber, New York (not far from Buffalo, New York), but spent most of her years in New Hampshire. Pat attended Seton Hill College (now University) in Greensburg, Pennsylvania, as a psychology major. She took a job as a social worker until she and her husband started a family, which grew to include five children. Four of the children still reside in the New England area in New York, New Hampshire, and Massachusetts.

Pat's daughter Carol Ott and family moved across country in 1987 to Clovis, California, when her husband took a job working for a friend. Carol settled in our area, along with her husband and two children, eventually adding three dogs and three cats to their household.

In 1991 Pat was diagnosed with Parkinson's disease ("PD"). She attributes the probable cause to her years of working on restoring furniture and using caustic chemicals, stains, and varnishes. Initially she did not need any medications, but eventually she added Sinemet, Mirapex, and Azilect to help control her PD needs. Over the years, balance issues became an increasing problem and Pat lost her driving license and independence. She was a successful realtor in New Hampshire, but had to give up that career due to her PD.

About six years ago, Pat decided to undergo the Deep Brain Stimulation Surgery. In September of 2009, Pat moved to Clovis to live with her daughter Carol Ott and family. Pat had several bad falls late last year, but when she stopped taking Sinemet and Mirapex in January, her balance improved significantly. Now Pat only takes Azilect, and only needs to use her walker when she is away from home for added stability. Pat is a patient of Dr. Bhatia, who encouraged Pat and Carol to attend our local PD support group.

Pat's hobbies include flower gardening, refinishing furniture, and reading. Presently she is reading The Heart is a Lonely Hunter. She enjoys mostly fiction works. Recently Pat and Carol refinished the dining room set that had belonged to Pat's parents many years earlier: a lovely drop leaf table with chairs and a china cabinet.

Pat's father also had Parkinson's disease, perhaps from his hobby as a gardener using pesticides.

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

Librarians:

Bill & Kathy Larkin

Newsletter Editor:

Ellen Jablonski

STEERING COMMITTEE

Bill & Barbara Burmeister
Anne Guenther
Ellen Jablonski
Doug & Sue Jackson
Riley and Linda Jones
Bill and Kathy Larkin
Joycelyn 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

Family Caregiver Alliance:
www.caregiver.org

Natl. Family Caregivers Assoc.:
www.thefamilycaregiver.org

Well Spouse Association:
www.wellspouse.org

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

Ellen Jablonski

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106 W. Paul Avenue
Clovis, CA 93612

www.FresnoParkinsons.org

(559) 593-9953

PARKINSON'S UNITY WALK: It's not too late to contribute:

The Fourth Annual *Parkinson's Unity Walk* was held April 24, 2010, at Blain Park in Visalia. It featured local musical groups and was well attended. Miriam Smith was the Chairperson for the event. Funds raised locally will be sent to the *National Parkinson's Unity Walk*. 100% of the funds raised nationally will go towards research to find the cause and a cure for Parkinson's disease. So far, donations made at this event total nearly \$24,251. The funds raised by these Walks, held all over the nation, will be dispersed to the Michael J. Fox Foundation for Parkinson's Research, the Parkinson's Disease Foundation, and five other nationally acclaimed Parkinson's research organizations. Make donation checks out to: *Parkinson's Unity Walk*, and mail them to **Central Valley Parkinson's Support Group, 4612 S. Linda Vista, Visalia, CA 93277**. Donations are 100% tax deductible: the 501(c) Tax ID# is 13-384-2415.

Synopsis of Our April 10, 2010, Meeting:

Russ Templeton and Barbara Burmeister emceed the meeting. It was acknowledged that April has been made the *official* Parkinson's Awareness Month. Volunteers serving our support group were thanked and a request was made for others to serve as backup volunteers.

For the past few years our Support Group has been very blessed to hold our meetings at The Bridge free of charge. The Bridge recently adopted a new policy to charge fees to outside groups for the use of their facilities. However, as an exception, they have kindly agreed to continue allowing us to use their facilities at no charge. We are very thankful for this gracious accommodation. Of course, it makes us aware that there are indeed costs to The Bridge in making the facilities available to us. We will therefore be taking a voluntary offering from members of our group who wish to help cover some of these costs at our May meeting.

Our featured speaker was **Perminder J.S. Bhatia, M.D.**, Board Certified Qualified Medical Examiner, Neuro-Pain Medical Center, Inc., 736 E. Bullard, Suite 101, Fresno, CA 93710, Office: (559) 437-9700; Fax: (559) 437-9799, Online: www.neuropain.com. Dr. Bhatia told us about the advancements made in Deep Brain Stimulation Therapy including a version in which only one battery is required, and there are versions where the device can be recharged by an external battery recharger rather than having to undergo surgery to replace batteries after about 5 years. He discussed the limitations as well as the drawbacks of the surgery. Afterwards Dr. Bhatia answered general questions about PD.

Attention Vietnam Vets: Late last year, the Department of Veterans Affairs added three more diseases—Parkinson's, ischemic heart disease, and B-cell leukemias—to the 12 other ailments and disorders it automatically considers to be service-connected for the more than 2 million vets who may have been exposed to the defoliant Agent Orange while serving in Vietnam. The VA is granting disability compensation to any veteran who suffers from any of these ailments—or to the widows of veterans who may have died of them—even if the veteran spent only one day in Vietnam.

Other diseases presumed linked to Agent Orange include Hodgkin's disease, type 2 diabetes, non-Hodgkin's lymphoma, prostate cancer and respiratory cancers.

For a full list of the diseases that may qualify a Vietnam veteran (or that veteran's spouse or widow) for disability compensation and VA health care, go to www.publichealth.va.gov/exposures/agentorange/diseases.asp

Note: Thousands of veterans who served in Korea from April 1968 through July 1969 may have been exposed to the same types of toxic defoliants used in Vietnam. They may also qualify for disability compensation.

By Dave Lindorff, May/June 2010 *AARP Magazine*

**Words of
the
Month:**
Soporific
(sə'n' ə rɪf'

TREASURER'S REPORT BY BARBARA BURMEISTER:

Fresno Parkinson's Support Group (GFPSG) Report: The March 24 – April 23, 2010, Wells Fargo Bank account shows a beginning balance of \$249.07. Debited from the account during this period were four checks totaling \$185.02 for April newsletter and newsletter-related expenses; and March and April meeting refreshment expenses. Deposited to the account was \$139.00 in donations from the April 13 Support Group meeting as well as a \$100.00 check from the family of two of our members for a total of \$239.00. This leaves an ending balance on April 23, 2010, of \$303.05. Monies donated directly to our Support Group are not tax deductible; however, they do help cover the cost of meeting and newsletter expenses. Thank you so much for your continued generous support.

Fresno Regional Foundation Report: The quarterly "Statement of Fund Activity" report for the period of January 1, 2010 – March 31, 2010, shows a beginning balance of \$3,971.06. During this period there were two donor gifts totaling \$45.00, unrealized gain in the amount of \$1.10, and interest/dividends in the amount of \$2.98 leaving a balance \$4,020.14. Deducted from the account was \$24.99 for the Fresno Regional Foundation's quarterly administrative fee leaving an ending balance of \$3,995.15. In April, a gift in the amount of \$50 was received. The intent of this gift was for the general operations of our organization. As of April 30, 2010, we have a balance of \$4,045.15 in our fund. Donations or gifts to our Support Group through the Foundation are tax deductible and can be made by check, Visa or MasterCard or on-line. 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 Fresno Regional Foundation's address is: 5250 N Palm Avenue, Suite 424, Fresno, CA 93704. Call (559) 226-5600 or go to www.fresnoregfoundation.org for additional information or to make a donation or gift online.

Resource of the Month: Since January 2008, husband and wife team Rich and Kim Rozek have been doing an online weekly radio broadcast about living with Young-Onset Parkinson's Disease on *Blog Talk Radio* out of New York. **Parkinson's Disease Talk Live (www.PDTALKLIVE.com)**. They've had over 100 broadcasts and are the most listened to online radio program regarding PD. They've interviewed members from APDA, Parkinson's Disease Foundation, Firefighters against Parkinson's, PAN (Parkinson's Action Group) among others. The program includes Parkinson's news, interviews, and the experiences shared with their listeners. Rich is 49 and was diagnosed with Young-Onset PD approximately nine years ago.

They are always looking for guests of interest to the Parkinson's community. If you're interested, they would love to have you as a guest. They usually prerecord the interview, unless you would like to be part of their quarterly live program. They currently get between 800 to 1,000 downloads/listeners per month.

Their program's site is: www.blogtalkradio.com/pdtalklive. E-mail: pdtalklive@live.com; Phone (219) 232-5322; Skype: PDTALKLIVE; mail The Pforce Network, 10769 Broadway, #229, Crown Point, IN 46307 They broadcast on the Blog Talk Radio Network, New York.

*They respect your privacy. A part of the Pforce Network - A Positive Force in Online Radio!
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Word of the Month: Bruxism (from the Greek *brugmó*, "gnashing of teeth") is characterized by the grinding of the teeth and is typically accompanied by the clenching of the jaw. It is an oral parafunctional activity that occurs in most humans at some time in their lives. In most people, bruxism is mild enough not to be a health problem. While bruxism may be a diurnal or nocturnal activity, it is bruxism during sleep that causes the majority of health issues and can even occur during short naps. Bruxism is one of the most common sleep disorders. There are studies showing that bruxism can be caused by diseases such as Parkinson's disease.