

Greater Fresno Parkinson's Support Group

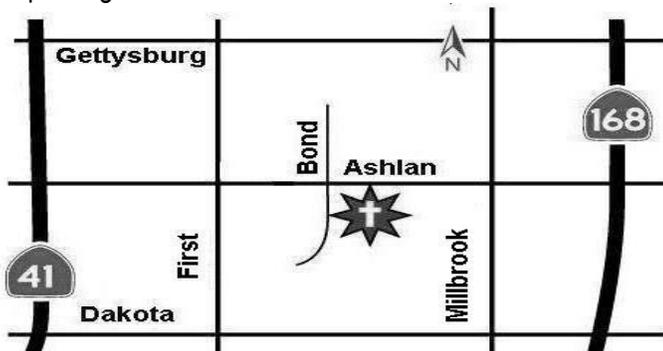
"Helping to optimize the quality of the lives of *People With Parkinson's* and their *Care Partners*."

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



SATURDAY, JULY 10, 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.



After-Meeting Get Together: At 12:30 pm after our July 10 meeting, let's gather to get to know one another better over a no-host lunch at Carrow's on 1484 E. Shaw and Sixth. See you there!

Chuckle of the Month

Don't let your worries get the best of you. Remember, Moses started out as a basket case!
www.Nubia_group.blogspot.com

Word of the Month:

pluripotent (plū-'ri-pə-tənt) *adjective*, not fixed as to developmental potentialities; *especially*: capable of differentiating into one of many cell types <pluripotent stem cells>.

OUR JULY PROGRAM:

Our speaker will be **Dr. M. A. Nezami** of **Pacific Medical Center of Hope, Inc:**

Pacific Medical Center of Hope in Fresno, California, is designed to assist patients suffering from Neurodegenerative Disorders such as Parkinson's, MS, and Dementia, using cutting edge modalities that can improve brain function. These may include hormone replacement therapy, detoxification, nutrients, and specific supplements that can affect brain function without side effects. Patients report that their function significantly improves with better ability to talk, walk, and less tremors in Parkinson's disease. At the same time, patients continue their relationship with their primary care provider or specialists.

Dr. Nezami is an M.D. graduated from residencies at USC and UCSF, and is a graduated fellow and a member of American Academy of Anti Aging and Regenerative Medicine. He is double board and certified in family medicine and regenerative and functional medicine.

He will be introduced by Bruce Medlin, one of our group co-leaders and a current patient of Dr. Nezami.

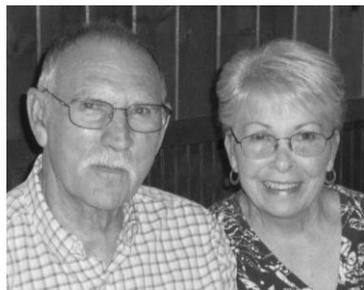
Resource of the Month

When someone who is 21-40 years old receives a diagnosis of Parkinson's disease, it is referred to as "young onset" Parkinson's disease and such a person is likely to want and need a different kind of education and support than someone who has been diagnosed later in life. **American Parkinson Disease Association's National Young Onset Center** and Web site offer you: programs and services that focus on education, networking and wellness; personalized and confidential one-to-one service; help managing young onset PD as effectively as possible so you are able to live well and stay strong!

www.youngparkinsons.org
(877) 223-3801

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: Jerry and Jewel Bain



Both Jerry and Jewel were born in Oklahoma, and both of their families eventually moved to Fresno, California. With several mutual friends in the neighborhood, they were introduced to one another when Jerry was 18 and Jewel was 14. Friends for many years, their relationship continued through Jerry's deployment with the Navy to the Philippines for 2 years.

When Jerry returned to Fresno, they were married within two whirlwind weeks, on July 11, 1954. Jerry continued with his career in the Navy, serving as an aircraft mechanic, most of his years in the Bay Area. He enjoyed his association with the "Weekend Warriors" – working with reservists on weekend assignments.

Jerry and Jewel welcomed three children into their family during their years in Alameda and Oakland, and moved back to Fresno when he retired from the Navy. They left the cool climate in the Bay Area and arrived in Fresno on July 7th, 1971 – on an incredibly hot summer day when the temperature was 108 degrees. What a shock! Their son lives in Colorado, one daughter lives in Reedley, and the other daughter lives in Fresno, right across the street from Jerry and Jewel. Jerry continued using his gifts and interests in machinery after his Navy retirement by working for many years as a Sears service tech.

It was when Jerry was still in his 30's that he was first confronted with medical trials. He was diagnosed with diabetes when he had his discharge physical from the military. His Parkinson's disease was diagnosed about 10 years ago, when Jerry was still in his 60's. Most recently Jerry was diagnosed with thyroid cancer, which has turned out to be a "family affair" due to a strong genetic factor. Several family members have now also been diagnosed with thyroid cancer within the past year. Recently both daughters and a granddaughter have had thyroid cancer surgery, and two great-grandchildren are scheduled for surgery this summer. Jewel and Jerry both feel that his diabetes is a bigger daily challenge than the Parkinson's (but not so big that he can't still enjoy his ice cream from time to time).

Former golfers and enthusiastic travelers, they now stay closer to home and enjoy family gatherings at least twice a month. They spend time in their garden, and look forward to an occasional dinner out with friends.

Jerry and Jewel have enjoyed attending our Support Group meetings, having received much helpful information from the programs and speakers. They are grateful about life – noting that because Jerry's illnesses are progressive, they have had time to more gradually adjust to changes. They are thankful for the abundant help and support they have received from each other, their family, friends, church, and most especially from the Lord Jesus Christ during their years "in sickness and in health" together.

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
Family Caregiver Alliance:
www.caregiver.org
Natl. Family Caregivers Assoc.:
www.thefamilycaregiver.org
Well Spouse Association:
www.wellspouse.org

FOR MORE INFORMATION,
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OR TO SUBMIT MATERIALS OR
SUGGESTIONS, CONTACT:

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Synopsis of Our June 12, 2010, Meeting: Barbara Burmeister and Russ Templeton emceed the meeting. Russ announced that if a PWP and his or her physician agree that their PD symptoms are temperature sensitive, and (as in many cases) require more than minimum cooling (or heating) during summer (or winter), PG&E has offered help. The power company will grant a larger base line allowance (cheapest rate) for energy used on your billing. Russ offered copies of the application form that were printed off the PG&E internet site to any that needed a copy. Additional copies can be obtained from their website at PG&E.com (click customer service, then brochures & forms, then medical baseline and life-support to download the form).

Robert Howk and his wife Marcella (Marcie) Downing of the Law Office of Howk & Downing, LLP, spoke to us about estate planning, life planning, Veterans' benefits, and other issues for Parkinson's patients and their families. Marcie's father is a Parkinson's patient himself. Robert and Marcella are local attorneys, practicing exclusively in the area of estate planning and elder law. They advised us on the ways that planning can improve quality of life while obtaining maximum benefits from Veterans' benefits and Medi-Cal.

Marcella recommended two websites for keeping family and friends informed about the condition and needs of one suffering a health event: www.lotsahelpinghands.com and www.caringbridge.org.

Copies of "Seniors and the Law" were distributed. To get a free copy, email seniors@calbar.gov or mail your request to **Seniors and the Law," Office of Media and Information Services, The State Bar of California, 180 Howard St., San Francisco, CA 94105-1639.**

Treasurer's Report by Barbara Burmeister

Greater Fresno Parkinson's Support Group (GFPSG) Checking Account Report: The May 26 to June 23, 2010, Wells Fargo bank Statement shows a beginning balance of \$368.58. Debited from the account during this period were three checks totaling \$164.19 for newsletter-related and meeting refreshment expenses. Deposited to the account was \$129.00 in donations. Transferred into the checking account from the GFPSG account held at the Fresno Regional Foundation was \$750.00; \$500.00 to replenish the checking account, and \$250.00 to be donated to *The Bridge* in thanks for allowing our Support Group to utilize their facilities without charge. The current balance in the checking account is \$1,083.39, with the \$250.00 check to *The Bridge* 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 were no gifts or donations made in June to the GFPSG fund held at the Fresno Regional Foundation. The GFPSG Steering Committee approved transferring \$750.00 from the Foundation account to replenish operating funds in the GFPSG Wells Fargo checking account. The current balance in our Foundation account is \$3,281.00.

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 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 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.fresnorefoundation.org to make a gift online.

Drug Makers to Share Data to Speed Brain Research

By Lisa Richwine – Jun 11, 2010

WASHINGTON (Reuters) – Major drug makers will share data from their clinical trials for Alzheimer's and Parkinson's disease in an effort to speed the development of new medicines to treat the brain disorders.

The database, a public/private partnership unveiled on Friday, will give academic and industry researchers worldwide access to information from more than 4,000 patients with neurodegenerative diseases.

Bringing the data together, rather than keeping pieces of it within each drug company, will give scientists a larger amount of information on how the diseases progress and how they differ in various patients.

Backers hope the approach will jump start research into treatments for some of the toughest and most common brain disorders. Despite decades of study, doctors still have few effective treatments for Alzheimer's disease, which affects more than 26 million people globally. It is the most common form of dementia.

An estimated four million people worldwide have Parkinson's disease, which causes trembling and other symptoms.

Information in the new database should help drug makers design more efficient clinical trials of potential treatments, said Dr. Raymond Woosley, president and chief executive of the Critical Path Institute, a nonprofit organization working to improve drug development.

"Some patients, for example, develop Alzheimer's in their 80's while for others it starts in their 40's," Woosley said. The disease probably evolves differently in those groups, but companies only have small numbers in each age range to study in their own trials.

"If you have 4,000 patients (in the database), you begin to have enough data to see their real course" and can target a drug to specific types of patients, Woosley said in an interview.

At a news conference to unveil the effort, Woosley said future clinical trials "will be smaller, they'll be shorter and yet far more likely to find successful therapies because of this database."

The project is coordinated by the Coalition Against Major Diseases, an organization of patient groups and 13 drug makers that is part of the Critical Path Institute.

Companies that have already contributed clinical data are Pfizer Inc, GlaxoSmithKline PLC, AstraZeneca, Johnson & Johnson, Novartis AG Sanofi-Aventis and Abbott Laboratories Inc.

Manufacturers agreed to participate because they realize "innovation no longer happens in one company's laboratory. It happens through constant interaction between scientists in the biopharmaceutical industry, patient advocacy organizations, academia and government," said Dr. Frank Casty, an AstraZeneca vice president.

Officials from the Food and Drug Administration, the National Institutes of Health and the European Medicines Agency serve as advisers.

FDA Deputy Commissioner Joshua Sharfstein said information gleaned from the data will help the agency and outside experts identify the best standards for future clinical trials.

The results "will allow safe and effective treatments to come to market and get to patients more quickly," he said.

NOTE: There will be no GFPSG meeting in August.