

Greater Fresno Parkinson's Support Group

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

HAPPY EASTER!!!

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

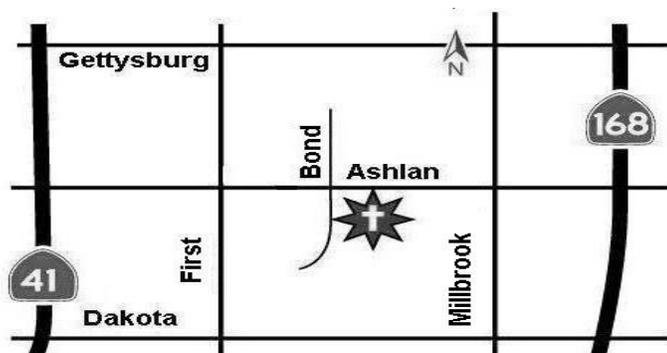


Our Next Meeting is on

SATURDAY, APRIL 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.



Chuckle of the Month

A Positive Outcome: A little boy was brought into the emergency room after ingesting part of a plug-in air freshener. After consulting Poison Control and monitoring him, the doctor wrote on his discharge, "Patient doing well. Ready to go home. Smells good!"

Submitted by Jan Templeton

OUR PROGRAM:

Neurologist **Dr. Permindar Bhatia**, Director of the Neuro-Pain Medical Center, 736 E. Bullard Ave., Suite 101, Fresno, CA 93710, Office (559) 437-9700, Fax (559) 437-9799, neuro736@sbcglobal.net, or neuropainphysician@sbcglobal.net.

Dr. Bhatia recently attended a national meeting on Parkinson's disease and updates on DBS. He is eager to share with us what he has learned and to answer our questions about Parkinson's disease in general.

ANNOUNCING THE NEW AND IMPROVED PARKINSON.ORG

Parkinson.org is the newly-redesigned online resource for the more than four million people worldwide living with the disease, their families, and health care professionals. It is sponsored by the National Parkinson Foundation (NPF) and is the official web site of the organization. NPF is dedicated to "Improving Care, Improving Lives" through research, education and outreach.

April is "Parkinson's Awareness Month"

On March 26, the U.S. Senate took an action long sought by the Parkinson's community: it designated April as "*Parkinson's Awareness Month*." This action signifies the importance of Parkinson's disease, and it recognizes Congress' commitment to finding better treatments and a cure for Parkinson's disease. Thanks to the actions of Senators Debbie Stabenow (D-MI), Johnny Isakson (R-GA), Mike Johanns (R-NE), and Mark Udall (D-CO), S. Res. 474 was passed unanimously, and this designation is now a national reality.

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: Arlene Beard



Arlene Beard grew up in Scottsdale, Arizona, enjoying her first pony "Alfalfa" (because the pony ate so much of it) and a 4-H Jersey cow named "Moo." Arlene happily rode her horse every day. In 1964 she graduated from Colorado State University with a Bachelor's in Animal Science. She was part of the CSU rodeo team, winning awards at national

intercollegiate rodeo finals in goat tying and barrel racing. She then worked as an agricultural chemist testing and formulating pesticides and herbicides (probably the cause for her Parkinson's disease).

Arlene married and moved to Kerman, enjoying skiing, scuba diving and softball.

After divorcing, she and her daughter Shawna Speake opened the first Paper Fantasy gift shop at First and Herndon. Adding a US Post Office became a huge draw, and other stores were added in Aptos, Fresno, and Clovis. Finally after 23 years, scoliosis and Parkinson's took their toll and she closed her last store, Bravata Home Décor, at Willow and Nees.

In 1998, Arlene and her daughter bought five acres together at Appaloosa Acres where the home is shared with three grandchildren; the oldest is a recent UC Davis graduate. Horses, chickens, dogs and cats round out the household.

Arlene's grandfather was the noted historian and author Charles A. Beard (An Economic Interpretation of the Constitution, and schoolbook Beard's Basic History of the United States).

In 1989 Arlene inherited her mother's 1928 "BIRD" biplane, so of course Arlene had to learn to fly it and took it to many fly-ins telling the story of how her mother overcame all the obstacles and prejudice of women flying in the 1920's and 30's. She's writing a screenplay of the story. Her mom and dad met at her mother's flying school, eloped in his biplane, and he gave it to her as a wedding present. She then won the Amelia Earhart Trophy race at National Air Races in Cleveland in 1935. The family still has the trophy and a beautiful picture of Melba Beard and Amelia Earhart.

Currently Arlene is traveling and camping with her 1957 vintage trailer which she hand painted with a mural of Monument Valley.

OFFICERS

Co-Leaders/Emcees:

Russell Templeton
Doug Jackson
Bruce Medlin

Treasurer

Barbara Burmeister

Membership Committee:

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Faye & Jack Smith

Care Partners Group Leader:

Anne Guenther

Librarians:

Bill & Kathy Larkin

Newsletter Editor:

Ellen Jablonski

STEERING COMMITTEE

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Doug & Sue Jackson
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Bill and Kathy Larkin
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Jack & Faye Smith
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WEBMASTER

Frédéric "Fredo" Martin
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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:

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PARKINSON'S UNITY WALK APRIL 24, 2010

The Fourth Annual *Parkinson's Unity Walk* will be held **April 24, 2010, 8:00 am to 12 pm**, at **Blain Park at 3101 S. Court Street, Visalia, CA 93277**. It will feature local musical groups. Bring your own refreshments. Mim Smith is 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. Make donation checks out to: ***Parkinson's Unity Walk***, and send them to **Central Valley Parkinson's Support Group, 4612 S. Linda Vista, Visalia, CA 93277**, or walkers may bring envelopes and pledged donations to the *Walk*. Donations are 100% tax deductible: the 501(c) Tax ID# is 13-384-2415. There is no set donation to participate in the *Walk*. A limited amount of event T-shirts will be available to purchase at the *Walk*. Best is to order them beforehand. To order T-shirts or for more information, call Pat at (559) 733-9916 or (559) 734-1017, leave your name, phone number, sizes of T-shirts and how many of each size. T-shirts sized Child through Adult 1X are \$15, Adult sizes XX or larger are \$18.

Synopsis of Our March 13, 2010, Meeting:

Fresno State Physical Therapy Master's Students Jennifer Hata, Jessica Maddox, and Kristy Brooks, are researching gait adaptations in individuals with Parkinson's disease during directional changes and dual tasking. They discussed the details of the study and signed up volunteers. If you are over 55 years old, have no other diagnoses or bones broken in the past year, and don't use a wheelchair, sign up for the one-day program to be held on the campus at Fresno State on a mutually convenient date and time by contacting Jennifer Hata, (559) 289-6777, jenhata@gmail.com.

Martin and Marianne Weil acknowledged the one-year anniversary of the Parkinson's exercise program at *San Joaquin Valley Rehabilitation*. Of the 30 or so members that signed up for the classes, about 15 People With Parkinson's attend. Day passes are \$7; if you become a member which includes use of their indoor pool, SJVR will waive the initiation fee.

A Care Partners breakout session was held by Anne Guenther with Yee Vue of the Valley Caregivers Resource Center, an organization which provides services such as respite care and home care planning. Meanwhile, those remaining at the general meeting shared tips and experiences such as using specially adapted eyeglasses or magnifiers for computer use; easing swallowing difficulties; the Lee Silverman Speech Therapy for PWP; concerns regarding driving; solutions for upset stomach helped by eating ginger or having your doctor change meds or dosing; and details of Deep Brain Stimulation—there may be a special support group forming especially for those who had DBS.

Oakhurst Area Parkinson's Support Group, (559) 760-0268. Meetings are held the second Tuesday of each month at the Yosemite Bank Community Conference Room. Start time is 10:00 am and everyone is asked to please be on time. Programs last one to one-and-a-half hours. Attendees are invited to join others afterward at a local restaurant to eat lunch and share stories of success and encouragement.

TREASURER'S REPORT BY BARBARA BURMEISTER:

GFPSG: The February 25 – March 23, 2010, Wells Fargo bank statement shows a beginning balance of \$403.38. Debited from the account during this period were two checks totaling \$100.00 for February and March miscellaneous newsletter-related expenses; and two checks totaling \$156.31 for the actual expense of printing and mailing the February and March newsletters. Deposited to the account was \$102.00 in donations from the March 13, support group meeting, leaving an ending balance of \$249.07. Outstanding is one check in the amount of \$27.50 for the March meeting refreshments, leaving an adjusted ending balance of \$221.57.

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: As of March 29, 2010, the "Greater Fresno Parkinson's Support Group Fund" account balance at the Fresno Regional Foundation was \$4,002.30, which includes two donations made in March totaling \$45.00. Donations or gifts to our support group through the Foundation are tax deductible and 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 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.

Dental Health of People With Parkinson's ("PWP"): Parkinson's disease ("PD") can pose challenges in dental treatment which can affect nutrition and increase risk for stroke, cognitive impairment, and weight loss. Oral hygiene requires eye-muscle coordination, digital dexterity, and tongue-cheek-lip control. PD symptoms like tremor, rigidity, and abnormal posture may make a dentist's exam difficult. Weakened swallowing ability can increase the risk of aspiration (choking) from some treatments. PWP who have been on meds like levodopa for several years may develop oro-buccal dyskinesias or teeth grinding. PWP may also have dry mouth which can worsen chewing difficulties or denture discomfort. Apathy, depression, and forgetfulness may lead PWP to pay less attention to dental health. PWP can require higher calorie intake. PWP may experience decreased appetite which often leads to a tendency to avoid nutrient-rich foods that require chewing well. It can also lead some PWP to develop a "sweet tooth" increasing the risk of cavities. PWP may have cognitive impairment which can lead to a decline in dental hygiene and may be *more* likely to miss dental appointments and *less* likely to report dental pain to their Care Partners or dentist. Use an electric toothbrush which provides the fine and repetitive motions. Prescription strength topical stannous fluoride gel treatments are a good preventive strategy. Mouthwashes are discouraged for PWP because of choking risks. If using mouthwashes is still an option, use non-alcohol based ones that use either chlorhexidine (consult your dentist) or baking soda. Make early morning dentist visits when waiting times tend to be shorter. Time your meds so you are at your best during your appointment. Plan several brief dentist visits rather than fewer, longer visits. As PD progresses, motor symptoms worsen and anxiety may increase, making home dental care and routine dental work more difficult. A neurologist will often be able to help in such situations, weighing the risks of medications with the potential benefit of a dental intervention. If invasive procedures, such as tooth restoration, are indicated, these should be undertaken as early as possible in PD's progression, to minimize risk. If general anesthesia is used, the recovery period for a PWP may take longer.

Word of the Month: trophic (derived from the Greek meaning "to nourish"). Trophic factors (also *neurotrophic factors* or *growth factors*) are proteins that promote the survival, growth, and function of neurons in the brain. Because the degeneration of dopamine neurons is the pathological hallmark of Parkinson's disease, these proteins are of great interest to Parkinson's researchers. During normal brain development, trophic factors are critical for the correct wiring of the nervous system. Trophic factors that have received significant attention in Parkinson's research include Glial cell-derived neurotrophic factor ("GDNF") and the closely related neurturin.