

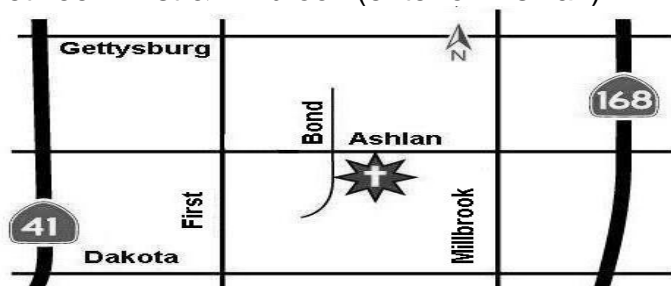
Greater Fresno Parkinson's Support Group

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

 **FEBRUARY 2009** 
Happy Valentine's Day!

Saturday, February 14, 2009
10:00 a.m. – 12:00 p.m.

In the Chapel of **THE BRIDGE** Evangelical Free Church, 3438 E. Ashlan Ave., Fresno, CA 93726, at the SE corner of Ashlan & Bond between First & Millbrook (enter on Ashlan).



OUR PROGRAM: Michael Dogali, MD, CM, FACS (www.michaeldogalimd.com), a neurological surgeon who has operated on more than 1,000 patients with a variety of functional disorders and has performed more than 400 Deep Brain Stimulation ("DBS") procedures. He is devoted to ongoing professional development and education in order to stay abreast of the latest in the field. His topic will be: "Surgical Treatment of Parkinson's Disease." He will also respond to questions about other medical treatments of PD.

PARKINSON'S-SPECIFIC EXERCISE CLASSES HAVE BEGUN!

San Joaquin Valley Rehabilitation ("SJVR") Fitness

11:00 a.m. – 12:00 p.m. Tuesdays and Thursdays at
7033 N. Fresno St., Ste. 101, Fresno, CA 93720.
Contact Luis Melgoza: (559) 431-2635, Ext. 119.

Resource of the Month: "Parkinson Pathfinder: The Newsletter of the American Parkinson Disease Association Information and Referral Center of Washington" www.waparkinsons.org or call (206) 277-5516 to subscribe.

Synopsis of our January 10, 2009, Meeting:

Ellen read the Prologue: "No More Nagging!" of the book "Making the Connection Between Brain and Behavior: Coping With Parkinson's Disease" by Joseph H. Friedman, M.D. which covers how difficult it is for People With Parkinson's ("PWP") to consciously control PD symptoms to overcome the inability to perform things usually done in "automatic pilot" such as posture, gait, and facial expression; hence nagging a PWP and expecting the advice to be followed for any length of time may be futile.

Ellen announced that **Community-Based Individualized Balance or Gait Retraining Programs** are available at the Dept. of Physical Therapy at CSUF 2/23/2009–4/22/2009. (559) 278-4148 ext. 2, www.csufresno.edu/physicaltherapy.

Max reviewed the services of the **California Telephone Access Program (CTAP) (800) 806-1191** available free (no income limits) to California residents with visual, hearing, speech, or mobility difficulties, including a bracelet device to alert by phone up to 6 persons you designate to be phoned when activating the alert if you've fallen, etc. *The bracelet alert-caller requires that your doctor certify to at least 2 of the above listed disabilities; e.g., mobility and hard of hearing (speech problems often exist during "off" times for PWP otherwise not speech impaired).*

Max further advised that as a PWP you may qualify for **free 411** (telephone number information and connect services) on your land line phone and your cell phone. Call customer service of your land line service and of your cell phone service for details.

Russ discussed some of the uses and advantages of the "**California Advance Health Care Directives**" ("CAHCD") and offered copies of the CAHCD to Support Group members to complete on their own or with their own attorney. Additional copies of the CAHCD will be available at our February Support Group meeting.

Segments were shown of the DVD "Move It: An Exercise and Movement Guide to Parkinson's Disease" by Kevin Lockette, PT; narrated by Wally Amos and including neurologist Dr. Yee, which covers: an overview of physical symptoms; medication in understandable terms; techniques for improved mobility including bed mobility, transfers & walking/freezing; adaptive devices for safer walking; exercise programs for PWP; and much more: www.parkinsonsmoveit.com, (808) (not 800) 262-1118.

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, because 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. You are encouraged to report negative side effects of prescription drugs to the FDA: www.fda.gov/medwatch, (800) FDA-1088.

Getting To Know VAN NOBLE:



Van was born in Fresno in 1950 and lived in Clovis until he was seven years old and the family moved to Fresno to make way for the future Highway 168. After ten years in the house in Fresno, the State changed the route and the new route went through the new house. In the time it took for the new highway to get under construction, Van graduated from McLane High School in 1968 and received his BS degree from CSUF in Mechanical Engineering in 1976. He married in 1973 and has two children: Shawn 32 and Kelly 31.

For 25 years Van worked in the plumbing and heating and air conditioning design field as a professional engineer.

Van was diagnosed with Parkinson's in 1996. He had been experiencing phantom odors (which continues but to a lesser extent), and he noticed that when he operated his PC mouse his index finger shook. Simple fix...change over to using the left hand—it wasn't shaking yet. Then, finally, while watching the Olympics he noticed Muhammad Ali walking to light the Olympic flame. Ali was shuffling as he walked and carried his right arm across his body, parallel to the ground. Van sat up and realized that *he* had started walking with his right arm held across his body and his right foot occasionally scuffed the ground when he took a step. He sometimes stumbled on uneven ground. It seemed like a good time to visit a doctor and have it checked out. After tests to rule out other diseases that it could be, Parkinson's disease was all that was left. The diagnosis was made in October 1996. The symptoms that were not recognized (the right finger tremor, the phantom odors, etc.) had begun 2 or 3 years earlier.

Van continues to participate in social activities and Bible study groups to stay connected with people and to help maintain friendships. He is on Disability and maintains as normal a life as possible. He reads, works in the yard, visits friends and makes new ones, exercises, walks, and attends church services. He tries to live his life as the Bible directs. It is his faith that sees him through the hard reality that he cannot do all the things he once was able to do. God has a reason for this "curve ball" and he is going to find out what it is and how it can be used to help people.

Word of the Month: Diaphoresis—profuse perspiration which can be due to Parkinson's disease or a side effect of medications (iatrogenic).

OFFICERS

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 Max Robinson
Co-Leader
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 Shirley Robinson
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 Jack & Faye Smith
 Stuart Snider
 Russell & Jan Templeton
 Anthony Turano

FOUNDING MEMBERS OF OUR PREDECESSOR GROUPS

Valley Parkinson's Support Group:
 Allen & Anne Guenther
 Max & Charlotte Wolfe
North Fresno Parkinson's Support Group: Dottie Rosenberg

WEBMASTER

Frédéric "Fredo" Martin
 Workingarts Marketing, Inc.™

PEER COUNSELORS FOR OUR CARE PARTNERS

Anne Guenther: (559) 322-7076
 Sue Jackson: (559) 434-7928
 Shirley Robinson: (559) 226-2673
 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 (559) 298-4080
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NEEDED ASAP: VOLUNTEERS TO PARTICIPATE IN A PD RESEARCH STUDY AT CSUF

Parkinson's Disease Research Study:

What is the Most Effective Cue to *Improve Gait* of People With Parkinson's Disease?

By: Yoshi Fujii, Physical Therapist

I need 25 *volunteer* participants for a research study to be held at *California State University Fresno* ("CSUF") to examine the immediate effect of visual, auditory, and attentional cues on gait (way of walking) under single and dual tasks in People With Parkinson's disease ("PWP") which will add new information for areas of research and assist in designing effective gait-training intervention for PWP. ***PD is characterized by a deficit of the basal ganglia which works during automatic motor activities such as walking. There is evidence that external cues can elicit motor activity without the basal ganglia motor system.***

The assessment tools that will be utilized for this study are the *Unified Parkinson's Disease Rating Scale* ("UPDRS") (a questionnaire that assesses motor disability, motor impairment, mental dysfunction, mood, and treatment-related motor and non-motor complications) and the *GAITRite System* (a 14-foot long walkway embedded with pressure-sensitive sensors that are connected to a computer to measure temporal and spatial parameters of gait such as walking speed, step length, step time, etc., via electronic recordings of each footfall which are then calculated and stored in the computer as participants walk across the pressure-sensitive mat.). Participants in the study will remain on their normal medication regimen throughout the research study.

Currently, the days during which I'll set one-hour appointments for individual participant assessments to review and sign an *Informed Consent* and to complete the *UPDRS* will be **February 11, 14, and 21, 2009.**

Inclusion criteria to the study include: (1) People diagnosed with Parkinson's disease; **(2) no age limit;** (3) able to walk a 14-foot path about 24 times without a walking aid (if necessary, participants can complete testing in two days); (4) have adequate vision and hearing; (5) absence of any severe comorbidity likely to affect gait; (6) no severe dyskinesias or prolonged off periods; and (7) ability to understand and follow simple directions. **Even if you don't have current gait problems, I want to examine what external cues most influence the gait of PWP.**

Studies have demonstrated the effectiveness of visual, auditory, and attentional cues on gait in PWP; however, there are limited studies that compared visual, auditory, and attentional cues under "single task" (just walking) and "dual task" (doing another task while walking). In our study, dual tasks include: "motor tasks" (walking while carrying a bag of groceries), "cognitive tasks" (walking while doing calculations out loud), and "visual cues" (white strips of tape placed transversely at about 18-inch intervals in relation to the *GAITRite System* walkway), "auditory cues" (a metronome with frequency set at 100 clicks per minute which is a standard value for normal elderly walking cadence as participants match each step with the beat of the metronome), and "attentional cues" (verbal instructions such as "walk with large steps"). Each participant will first walk with no cue (single task), then will walk while receiving visual, auditory, and attentional cues. The participant will do the same under dual tasks (both motor and cognitive tasks). A total of two trials will be taken for each walking condition which totals 24 walks along the 14-foot *GAITRite System* walkway for a total distance of about 325 feet with as many rests as needed.

Please call me or e-mail me if you want to participate in this study. I would very much appreciate it. Thank you.

Yoshi Fujii, PT, Phone: (559) 304-9637, E-mail: yoshifujii@hotmail.com

"FRONTLINE" report on Parkinson's: "My Father, My Brother and Me"

Produced by Dave Iverson was aired February 3, 2009, on PBS.

"After learning he has Parkinson's disease, a degenerative neurological disorder affecting 1 million Americans, journalist Dave Iverson sets off on a personal journey to understand the disease that's taken such a toll on his family."

The entire film is available now on the website at: www.pbs.org/wgbh/pages/frontline/parkinsons/

PBS is interested in having people participate in an ongoing electronic conversation about this topic on the Frontline website.

Treasurer's Report by Barbara Burmeister: The January 27, 2009, Wells Fargo Bank Statement shows a Beginning Balance of \$449.84. Debited from the account was a cleared check in the amount of \$62.07 for December meeting expenses. Credited to the account were donations totaling \$206.00. The Statement shows an Ending Balance of \$593.77. A check in the amount of \$50.00 for a GFPSG-approved monthly stipend for January is outstanding, leaving an Adjusted Ending Balance of \$543.77. Your donations are very much appreciated!

Fresno Regional Foundation: The balance in the "Parkinson's Support Fund" as of February 6, 2009, is \$3,125.25. This balance reflects \$435.00 in gifts and bequests credited to the account in January 2009 (thank you!) and expenses totaling \$649.22 debited from the account. A breakdown of the expenses follows: 1) \$446.67 for the purchase of a media projector; 2) \$104.14 for educational materials such as the "Parkinson's Disease & Activities of Daily Living" DVD by John Argue, "Move It" (DVD and book); and two used copies of "Parkinson's Disease and the Art of Moving"; 3) \$17.55 for newsletter copy-work; 4) \$52.50 postage for the January newsletter; and 5) \$28.36 for the January meeting refreshments.

THE VICTORY SUMMIT

AN INTERACTIVE SYMPOSIUM DESIGNED TO INFORM AND INSPIRE PEOPLE LIVING WITH PARKINSON'S DISEASE

Thursday, March 12th, 2009

Doubletree Hotel San Jose
2050 Gateway Place,
San Jose, California 95110

\$20 per person (breakfast, lunch, program materials, valet parking, and all day access to onsite Health Fair).
Scholarships are available! For more details and to Pre-Register: (800) 655-2273 or online www.theipi.org.

Information about: the latest research, the importance of speech therapy, the benefits of exercise, and the latest news related to DBS and its effects on quality of life.

Inspiration by: Parkinson's Institute's CEO and Founder Dr. J. William Langston; Parkinson's Institute's Directors of Research: Dr. Caroline Tanner (clinical), and Dr. Dinato DiMonte (basic), and Clinical Director Dr. Melanie Brandabur; Stanford University's Neurosurgeon Dr. Jaimie Henderson and Director of Movement Disorders Center Dr. Helen Bronte-Stewart; Davis Phinney, Retired professional cyclist and Parkinson's disease quality of life advocate.

Preliminary Agenda:

7:30 – 8:00	Pre-Session Registration
8:00 – 8:45	Pre-Session PD 101 newly diagnosed, basics about PD, vocabulary, medication: Dr. Melanie Brandabur
8:00 – 9:00	Arrival and Registration
9:00 – 9:30	Introduction: J. William Langston, MD, & Victory Summit Video
9:30 – 9:40	Sit and stretch alignment with Marilyn Basham
9:40 – 10:10	Dr. Helen Bronte-Stewart, Stanford University
10:10 – 10:30	Morning Break
10:30 – 11:00	Dr. Jaimie Henderson, Stanford University
11:00 – 11:10	Learn to talk LOUD with Randy Hoffman
11:10 – 11:40	Science Overview with Dr. Caroline Tanner and Dr. Dinato DiMonte
11:40 – 12:10	Q & A session with morning speakers
12:10 – 12:40	Lunch is served, musical entertainment provided
12:40 – 1:15	Davis Phinney, Elite Cyclist and Parkinson's disease quality of life advocate
1:15 – 1:45	Post Lunch time to browse Health Fair and get to breakouts
1:45 – 2:45	Care for caregiver, Marilyn Basham & Brandan Nguyen Young onset panel, Dr. Grace Liang, Davis Phinney Spirituality and PD Clinical Trials, Dr. Melanie Brandabur
2:45 – 3:15	Break to get between sessions and browse health fair
3:15 – 4:15	Nutrition for PD, Dr. Grace Liang Atypical PD, Dr. Melanie Brandabur, Amy Manning-Bog, PhD Voice Therapy, how to be Loud – Randy Hoffman Latest in research: Tetrud, Schuele, Goldman, Quik
4:15	Seminar Concludes

Transportation options from Fresno are being explored. Call Max (559) 226-2673.