

# Greater Fresno Parkinson's Support Group

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

Our group meets the second Saturday of every month, taking the month of August off.

 **Our Next Meeting is on** 

**Saturday, October 10, 2009**  
**10:00 a.m. – 12:00 p.m.**

## OUR PROGRAM:

We plan to have two related presentations on the value of exercise:

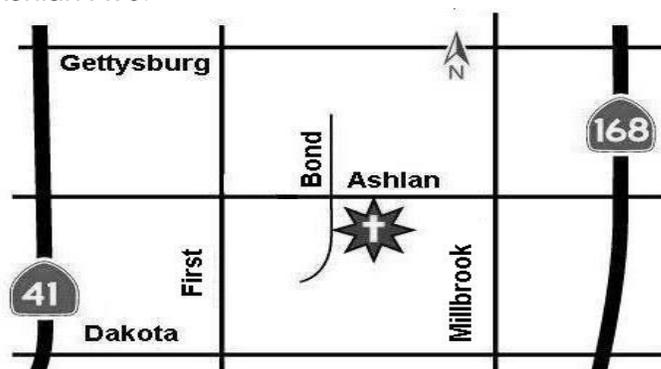
One will be a description of available training for People With Parkinson's ("PWP") in so-called "Fall Proofing." This training is not limited to PWP; it could be used by anyone who has a problem with balance or falling, which can be dangerous. It would include learning techniques to reduce the likelihood of falling, and ways in which to control a fall so as to minimize any damage.

Second, we plan to have a discussion and demonstration of the computerized exercise program developed by Nintendo, under the brand name "Wii." This allows individuals (even those having limited mobility) to engage in "virtual" sports like bowling, golf, baseball, and tennis. The computer program translates the limited motion of the player into a screen image that is both entertaining and a helpful tool for enjoying the benefits of motion. Additionally it provides opportunity for fellowship and friendly competition. As mentioned in a recent Newsletter, there have been PD clinical studies indicating "Wii" can be advantageous for PWP.

Also, we expect to have an opportunity for general questions and feedback during our meeting time.

## WHERE:

At THE BRIDGE EVANGELICAL FREE CHURCH in the atrium to the left of the Chapel, second floor, room 212-213, reached via the elevator, 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 plumber attended to a leaking faucet at the neurosurgeon's house. After a two-minute job, he demanded \$150. The neurosurgeon exclaimed, "I don't even charge that amount and I'm a brain surgeon." The plumber replied, "I agree. You are right! I didn't charge that much either when I was a surgeon. That's why I switched to plumbing."

## Get Your Daily Recommended Amount of Endorphins:

Since Parkinson's disease depletes feel-good dopamine in the brain, it is extra important that People With Parkinson's supplement with as much humor as possible. Please come to our meetings prepared with a joke or amusing anecdote to fill any extra time during our meetings. One source is: [humorvault.tripod.com](http://humorvault.tripod.com).

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 LARRY AND EMMA EDWARDS:



Larry was born in Arkansas in 1933; his family moved to Clovis, California, in 1951. Emma was born in Oroville, California, and her family came to Clovis when she was in 3<sup>rd</sup> grade. Both graduated from Clovis High School, Larry in 1953 and Emma in 1954. Surprisingly, they did not know each other in high school.

Larry was a member of the National Guard in high school and was drafted into the army after graduation. He was sent to Germany where he served in the military police. Emma went to beauty school and went to work. Larry and Emma met in 1957 through a mutual friend and they married in April 1958. They celebrated their 50<sup>th</sup> anniversary taking their children, their children's spouses, and grandchildren on a cruise. Larry and Emma lived in Fresno 47 years. In 2005 they downsized and moved back "home" to Clovis.

Larry and Emma had a son and two daughters. Their son Larry Glen passed away in February 2009. Their daughters, Suzanne and Barbara, live in Clovis. Each has three children. Suzanne is employed with Clovis Unified working with severely disabled children. Barbara had a stroke in 2008 and is recovering. She is a talented photographer and has been involved teaching an early childhood program in Clovis Schools.

Larry worked at Fresno Dodge for 20 years and retired in 1995 at age 62. He is quite proud of the many awards he received from Chrysler and Dodge. Emma retired from Clovis Unified in 1998. She had gone back to college for a degree in early childhood development and worked in the program with teenage parents that were students who had babies while still in high school. She also volunteered at St. Agnes hospital, worked in the gift shop, was treasurer for the guild, and was the Jr. Volunteer Advisor. Emma was awarded her 1,000-hour pin.

Larry was diagnosed with Parkinson's about 6 years ago. It started with a tremor in his leg and hand, then a masked facial expression, his walk became very slow, and his body stooped over. He also started getting lost in places he had been for years. It took about three years to find the right diagnosis. Larry and Emma belong to Kaiser Permanente and have a great network of doctors. They are in Kaiser's Chronic Care Management Program which they highly recommend.

They have a cabin at Shaver Lake and love "chilling out" with their grandchildren there. Larry had to stop fishing and hunting and no longer goes there in the winter because of the snow and uneven ground. They love to travel and cruise. Larry has to use a wheelchair but found they could still have a great time. You just have to change and adjust a few things.

Larry and Emma attend church and Sunday school at The Bridge. They heard of our Parkinson's Support Group from Max and Shirley Robinson. They are dealing with Parkinson's one day at a time and pray that some day there will be a cure. They know that God has a plan for each one of us.

### OFFICERS

#### Interim Leader/Emcee:

Russell Templeton

#### Treasurer/Alternate Emcee:

Barbara Burmeister

#### Membership Committee:

Sue & Doug Jackson

Faye & Jack Smith

#### Care Partners Group Leader:

Anne Guenther

#### Co-Librarians:

Bill Houk

Joycelyn Lock

Tony Turano

#### Newsletter Editor:

Ellen Jablonski

### STEERING COMMITTEE

Barbara Burmeister

Allen & Anne Guenther, Emeritus

Bill Houk

Ellen Jablonski

Doug & Sue Jackson

John Klassen

Joycelyn Lock

Bruce Medlin

Max & Shirley Robinson, Emeritus

Dottie Rosenberg, Emeritus

Jack & Faye Smith

Stuart Snider

Russell & Jan Templeton

Anthony Turano

Max & Charlotte Wolfe, Emeritus

### 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

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**(559) 593-9953**

## **SPEECH THERAPY PROVIDED BY SAN JOAQUIN VALLEY REHABILITATION**

Earlier this year, our Group Member Kirby Eskelsen completed the *Lee Silverman* program, a 4-week long, 16-session course of speech therapy at San Joaquin Valley Rehabilitation. As many of us with Parkinson's disease progress through the stages of our affliction, our speech becomes softer and less easily understood by others. The *Lee Silverman Voice Treatment* program is designed specifically to help us "speak up."

Kirby says the therapists were friendly and highly qualified. Though he has other problems with his speech that are also Parkinson's related, he says the course was definitely worthwhile and has made him much more aware of his vocal volume.

If you decide to try the *Lee Silverman* program, Kirby says to be prepared for an intense four weeks that requires not only participation at the rehab facility, but also much practice time vocalizing at home.

Ask your neurologist if he/she thinks you might benefit from some sessions of speech therapy. As the therapists remind us: "Think Loud!"

**Synopsis of Our September 12, 2009, Meeting:** Dr. Robert Calmes gave a wonderful presentation focused on sleep issues that plague many People With Parkinson's ("PWP"), and he answered general questions about Parkinson's disease. Highlights include:

It's been found that most people with Rapid Eye Movement ("REM") disorder eventually get Parkinson's disease ("PD"). Benadryl can help relieve REM disorder and early PD but can cause dry mouth and constipation in which case your doctor could prescribe Klonopin. For insomnia, meds such as Ambien, Ambien CR, Lunesta, and Dalmane can be prescribed, but they have habituating properties. Melatonin is helpful for many people; start with 10mg doses. Very common myoclonic jerks (involuntary twitching or spasm of a muscle or muscles) can interfere with sleep. It may be necessary for PWP to take PD meds during the night so PD symptoms won't keep them up.

Most PD meds can *cause excessive* daytime sleepiness. Try caffeine (regular coffee has 80mg, instant coffee has 60mg, most sodas have 20mg, Mountain Dew soda has 55mg, 7-up has none). If that doesn't help, your doctor may prescribe Provigil or Nuvigil. Amantadine provides more energy and helps stop involuntary movements such as dyskinesias.

It was thought that Sinemet wears off and can build a tolerance after about 5 years, but that didn't pan out; you just need to take more Sinemet to achieve relief from PD symptoms.

PWP generally don't have *hallucinations*, they have *illusions*: they are not seeing what is *not* there but misinterpret what *is* there. This happens more often during evenings which is called "sundowner effect." Antipsychotics such as Seroquel, Thorazine, or Clozaril may be prescribed. Problems with memory may be helped by either Aricept or Exelon. For nausea, Tigan works well for PWP.

Supplements such as CoQ10, vitamin E, various fruit juices such as açai claiming PD cures, etc. have not been proven to help PD symptoms. Dr. Calmes revealed that most Parkinson's meds and treatments have an unfortunate side effect of financial poverty.

Dr. Calmes provides Deep Brain Stimulation ("DBS") setting adjustments for DBS patients. If you don't respond well to PD meds or have dementia, DBS is not recommended.

Robert Calmes, M. D., 1313 E. Herndon Ave., Ste. 205, Fresno, CA 93720-3306, (559) 435-0311, Fax (559) 435-1708

Another Chapter ! Kirby Eskelsen and Ellen Jablonski tied the knot 09/19/09 at Burney Waterfalls.

### **Sinemet (Carbidopa/Levodopa) and Timing of Meals:**

Sinemet is made up of *levodopa*, which enters the brain and is converted into dopamine, and of *carbidopa*, which increases the effectiveness of *levodopa* and prevents or lessens many of the side effects of *levodopa*, such as nausea or vomiting. Many People With Parkinson's ("PWP") find no difference in the effectiveness of Sinemet as to timing of meals or limiting protein intake. This could change over time. You'll have to experiment on your own as to what works for you: It is generally recommended that PWP take Sinemet on an empty stomach at least 20 minutes to ½ hour *before* meals, or 1 to 2 hours *after* meals. Some PWP notice problems only when they eat red meat; others are more sensitive to any source of protein. Try shifting your protein meals closer to sleep time, or eat smaller more frequent meals to maximize Sinemet's effectiveness. Separate your dose of Sinemet as many hours as possible from any iron supplements or products that contain iron because iron can reduce the amount of carbidopa and levodopa available to the brain.

### **TREASURER'S REPORT BY BARBARA BURMEISTER:**

**GFPSG:** The August 26 – September 24, 2009, Wells Fargo Bank Statement shows a Beginning Balance of \$271.07. Debited from the account during this period were three checks totaling \$200.80. Credited to the account were \$140.00 in donations made at the September Support Group meeting; and a \$500.00 grant from the GFPSG Fund held at the Fresno Regional Foundation, to replenish the Support Group's Wells Fargo checking account, leaving an ending balance of \$710.27. Outstanding are two checks totaling \$120.94 for Newsletter-related expenses, leaving an Adjusted Balance of \$589.33.

As indicated in the September newsletter, our monthly expenses exceed our monthly donations by approximately \$40.00 per month, resulting in our Wells Fargo checking account balance being slowly depleted over this past year. I would like to thank you for your generous donations in September; our expenses in September were \$144.54, and our donations were \$140, up considerably from our past average of \$97.50 per month.

Although monies donated directly to our Support Group are not tax deductible, they do help cover refreshment and Newsletter-related expenses and are greatly appreciated. Thank you so much for your continued generous support.

**Fresno Regional Foundation:** The "Parkinson's Support Fund" Balance on August 28, 2009, was \$3,733.00. There was one gift received in the month of September in the amount of \$50.00. A \$500.00 check was disbursed from the account to replenish the GFPSG Wells Fargo checking account. The current balance as of September 28, 2009, which does not include September fees or earnings, is \$3,401.25. Donations and gifts made to our Support Group through the *Foundation* are tax deductible. Call (559) 226-5600 or go to [www.fresnoregionfoundation.org](http://www.fresnoregionfoundation.org) for additional information.

**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.

### **IN MEMORIAM**



*Avalynn Chapman*  
*Carol Lewis*  
*Richard Owens*

