

# Greater Fresno Parkinson's Support Group

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

We meet the second Saturday of each month **except August and November** or unless otherwise notified.

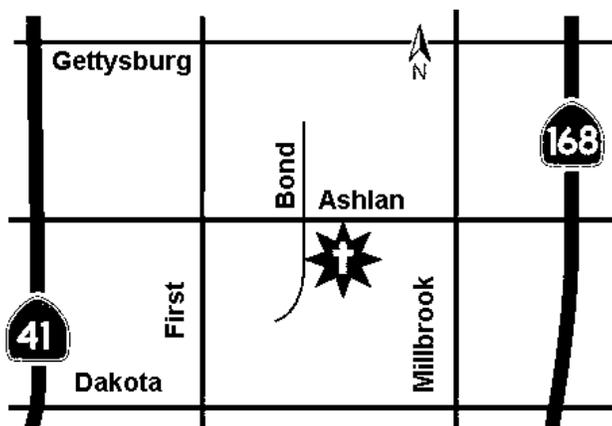
## HAPPY NEW YEAR!

 Our next meeting is: 

**SATURDAY, JANUARY 12, 2013**

**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.



**BRING ON THE CURE!**

### OUR JANUARY 12, 2013, PROGRAM

The speakers for the January 12 meeting are from **American Ambulance Service**. The main speaker is *Edger Escobedo*. They will cover many topics for us and explain their procedures. They will answer questions like how to be prepared for an emergency, what insurance covers payments, geographical area covered by American Ambulance, etc.

Refreshments will be available.

We have an extensive lending library of books, CD's, pamphlets, etc. Librarians Mac and MaryAnn MacDonald can assist you. We appreciate donations.

Our GFPSG Website is being updated, and is planned to be back online in February 2013.

### AFTER-MEETING GET TOGETHER

Come join us for a no-host lunch at 12:15 pm after our Support Group meeting. We will gather at Huckleberry's at 222 E. Bullard Ave., Fresno, CA 93710, just east of Highway 41, in the banquet room. (599) 440-9045.

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.

## TREASURER'S REPORT BY BARBARA BURMEISTER

### Greater Fresno Parkinson's Support Group (GFPSG) Checking Account Report:

The November 28 – December 26, 2012, Wells Fargo Bank Statement shows a beginning balance of \$1,778.92. Credited to the account in December was \$210.00 in donations and proceeds from the White Elephant sale at the Christmas potluck. Debited from the account during the statement period were three checks totaling \$177.75 for November newsletter expenses. The ending Statement balance was \$1,811.17. .

*Monies donated directly to our Support Group are **not** tax deductible; however, they do help cover the cost of newsletter, refreshment, and operating expenses. Donations made to the Parkinson's Support Group fund held at the Fresno Regional Foundation are tax deductible (see information below).*

If you have an email account, but receive a hard-copy of the Newsletter, please contact our Newsletter editor Ellen Jablonski to have your Newsletter delivered electronically. This would reduce the expense of printing and postage, and would also save Ellen valuable time.

**Fresno Regional Foundation (FRF) Fund Report:** There were no donations made to the Greater Fresno Parkinson's Group Fund held at the FRF in December. We started 2012 with a Fund balance of \$4,758.85. Revenue to date includes \$400.00 from Gifts/donations and \$37.97 earned from Dividends and Interest. Expenses/Debits to date include \$92.04 in Foundation Administrative/Investment Fees; as well as \$2,500.00 from the FRF Support Group Fund to replenish the Wells Fargo checking account (\$1,000.00 in January, and \$1,500.00 in August). As of December 31, 2012, the FRF Parkinson's Support Fund Statement shows an ending Fund balance of \$2,604.78.

**Consider making a tax-deductible donation to support our Greater Fresno Parkinson's Support Group.** Donations or gifts to our Support Group through the Fresno Regional Foundation are tax deductible and can be made online, or by check, Visa, or MasterCard. 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.fresnoregfoundation.org](http://www.fresnoregfoundation.org) to make a gift online.

### OFFICERS

#### Co-Leaders/Emcees:

Doug Jackson  
Bruce Medlin

#### Treasurer:

Barbara Burmeister

#### Hospitality:

Megan Bateman

#### Librarians:

Mac & MaryAnn MacDonald

#### Membership Committee:

Sue & Doug Jackson  
Faye Smith

#### Newsletter Editor:

Ellen Jablonski

#### Care Partners Group Leader:

Anne Guenther

### STEERING COMMITTEE

Megan Bateman

Arlene Beard

Bill & Barbara Burmeister

Winston Field

Anne Guenther

Ellen Jablonski

Doug & Sue Jackson

Riley and Linda Jones

Mac & MaryAnn MacDonald

Bruce Medlin

Faye Smith

Bob & Dorothy Starr

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

Fresno-Madera Area Agency  
on Aging: (800) 510-2020

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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NEW EMAIL: [bnb9157@att.net](mailto:bnb9157@att.net)

106 W. Paul Avenue  
Clovis, CA 93612

[www.FresnoParkinsons.org](http://www.FresnoParkinsons.org)  
(559) 593-9953

**Synopsis of our December 8, 2012, GFPSG Meeting:** We enjoyed a bountiful potluck, we played games, and we raised funds via a White Elephant Sale.

**BE PART OF THE ANSWER TO PARKINSON'S DISEASE.  
REGISTER WITH FOX TRIAL FINDER AND FIND THE CLINICAL TRIALS THAT NEED YOU.**

Participating in clinical trials is one of the most important ways patients and their loved ones can help accelerate treatment breakthroughs. Underenrollment in trials slows research progress—and patients pay the price in terms of higher costs and longer time horizons to therapeutic breakthroughs. Across all diseases, 80 percent of clinical trials finish late due to difficulties enrolling participants. Even more alarming, nearly one-third of trials fail to recruit a single subject and cannot ever begin.

The Parkinson's community is eager to take action and help speed the cure. But real-world obstacles can get in the way. Fox Trial Finder, a new Web tool, makes it easier to get involved. Until now, it's been hard to find the trials in your area that need someone with your specific medical history. Fox Trial Finder does the work for you, making it quick and easy to connect with the right trials. And your privacy is always assured.

**HOW IT WORKS**

**Find Better Matches with Less Work:** Visit Fox Trial Finder and complete a profile with basic information about yourself (such as location and some medical history). You'll immediately receive a list of trials in your area that need someone like you. Because Fox Trial Finder is committed to including every Parkinson's clinical trial, you can rest assured you're seeing the most complete list of trials near you that are a good match to your profile.

**Make Quick, Easy Connections with Trial Teams:** Every trial on Fox Trial Finder includes contact information for the study coordinator so that you can reach out directly. A built-in secure messaging system lets you connect anonymously with trial teams who have registered on the site.

**Your Privacy is Assured:** Your privacy is of the utmost importance. Fox Trial Finder uses state-of-the-art security protocols to ensure that your identity remains confidential. Your name, phone number or email address is only revealed when you share it with a trial team member.

**Connect with Trials that Haven't Even Begun Yet:** No matches? Sometimes it happens. Once you've completed your anonymous profile, save it and let us do the work. Fox Trial Finder will email you whenever a new trial begins that could be a good match for you. New trials start recruiting every month. Also, remember to update your profile at least once a year, or whenever you participate in a new trial or change your location or medical regimen.

Be part of the answer. Complete a profile and find your trial matches at [WWW.FOXTRIALFINDER.ORG](http://WWW.FOXTRIALFINDER.ORG) today!

**IN MEMORIAM**

Betty Pendergrass Wipf  
April 16, 1926 -  
December 27, 2012

**Word of the Month**

**Executive functions** are mental skills needed in everyday life such as planning, reasoning, decision-making, organizing, and problem-solving. Working memory, the ability to evaluate information, goal-directed activity and judgment are also executive functions. These skills are controlled by the brain's prefrontal cortex.

**Chuckle of the Month**

One weekly newspaper printed the following correction: "We apologize for the embarrassment caused by referring to Jonathan Foley as chief vile clerk at City Hall. He is, of course, the chief file clerk at City Hell."

## **AFFiRiS AG: Parkinson's Vaccine -- Worldwide First Clinical Study in Vienna**

The Sacramento Bee - The worldwide first clinical trial for the development of a Parkinson's vaccine has now been started by AFFiRiS AG. The vaccine called PD01A is directed against alpha-Synuclein, a protein considered causing the onset and progression of the disease, and is currently being tested on Parkinson's patients in a Phase I trial. The vaccine holds out the prospect to deliver a causative treatment of Parkinson's for the first time. Its potential for success prompted the US-American Michael J. Fox Foundation to generously support the development of PD01A financially. Taking place in Vienna and involving up to 32 patients, the primary endpoints of the trial are safety and tolerability of PD01A.

AFFiRiS AG announced today the start of the Phase I study of its Parkinson's vaccine candidate PD01A. This vaccine represents the first agent worldwide aiming at disease modification of Parkinson's rather than addressing symptomatic improvement only. PD01A targets a protein called alpha-Synuclein (alpha-syn) which plays a key role in the onset and progression of Parkinson's. The vaccination aims to educate the immune system to generate antibodies directed against alpha-syn. The trial will be conducted at the Confraternität Privatklinik Josefstadt in Vienna and will involve up to 32 patients.

Dr. Walter Schmidt, CEO of AFFiRiS, comments on the progress of the Parkinson's project: "Worldwide, for the first time immunotherapy is applied for the treatment of Parkinson's. It is a so-called "First-in-Man" and "First-in-Kind" trial, because PD01A is the first medication worldwide aiming for clinical efficacy by modulating the metabolic pathway of alpha-syn. Even in its preliminary stages, this new treatment concept was highly appreciated, as the renowned Michael J. Fox Foundation assented financial support to a total of USD 1.5 million. Hence, this is one of the few projects outside of the USA considered worthy of support by the foundation."

This recognition is remarkable as the vaccine-candidate of AFFiRiS has the potential to treat the cause of Parkinson's for the first time. Since the approval of L-DOPA some 50 years ago, any other therapeutic intervention followed the same concept: the substitution of the neurotransmitter dopamine. Accordingly, all medications for Parkinson's so far can impact on the symptoms only, but none of them can modify the course of the disease.

Based on today's scientific understanding, Parkinson's is caused by deposits of pathological forms of alpha-syn in the brain. A reduction of the brain's alpha-syn aggregates is believed to have a beneficial impact on the progress of the disease. PD01A shall accomplish that upon the induction of antibodies that are targeting alpha-syn, to neutralize its toxic impact.

Dr. Frank Mattner, CSO of AFFiRiS: "PD01A is based on our AFFITOME®-technology, which already identified our lead vaccine developments in the field of Alzheimer's. This technology delivers not only a single vaccine for the treatment of a certain disease but a whole pool of product candidates with excellent safety profiles and exactly fine tuned specificities. Therefore, we apply our strategy of "clinical maturation", meaning that we investigate several vaccines against a certain disease in clinical testing to ensure that the best vaccine for humans will be developed."About AFFiRiS AG" (as of June 2012):

Based on the company's own patent positions, AFFiRiS develops tailor-made peptide vaccines for Alzheimer's disease, Atherosclerosis, Parkinson's disease, hypertension and several other conditions with urgent requirement for new treatments and attractive market volumes. Alzheimer's is the current lead indication. A license and option agreement for the Alzheimer's vaccine programme was concluded with GlaxoSmithKline in October 2008, triggering an up-front payment of EUR 22.5 million. The contract envisages (milestone-dependent) payments of up to EUR 430 million. An initial milestone payment of EUR 10 million was made in October 2009 followed by EUR 3.5 million as announced in February 2011. AFFiRiS currently employs 85 highly-qualified staff at the Campus Vienna Biocenter in Vienna, Austria (<http://www.affiris.com>).

Contact AFFiRiS AG: Julia Bock Karl-Farkas-Gasse 22 1030 Vienna, Austria T +43(0)1-798-15-75-303 E [julia.bock@affiris.com](mailto:julia.bock@affiris.com) W <http://www.affiris.com> Editing & Distribution: PR&D - Public Relations for Research & Education Mariannengasse 8 1090 Vienna, Austria T +43(0)1-505-70-44 E [contact@prd.at](mailto:contact@prd.at) W <http://www.prd.at>

<http://www.sacbee.com/2012/06/05/4539144/affiris-ag-parkinsons-vaccine.html>