

# *Parkinson's Patients Support Groups, Inc.*

*Spring Quarterly 2005*

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*2nd Annual*

## *2nd Annual* **Parkinson's Walk**

**FUND THE RESEARCH – FIND THE CURE!**

Sunnyvale, CA **Saturday, May 14, 2005**

Registration: 9 AM --- Meet at parking lot of Target  
(corner of Sunnyvale & Iowa)  
Downtown Sunnyvale

Walk begins: 10 AM **Total distance of walk: 1.2 miles**

For a walker registration form: **[www.parkinsonsinstitute.org](http://www.parkinsonsinstitute.org)**

***PRIZES AWARDED TO TOP FUNDRAISERS!***

Proceeds support:

- ☞☞* Parkinson's Disease Foundation
- ☞☞* The Michael J. Fox Foundation for Parkinson's Research
- ☞☞* The Parkinson Alliance
- ☞☞* The Parkinson's Institute
- ☞☞* National Parkinson Foundation
- ☞☞* Parkinson's Action Network
- ☞☞* American Parkinson Disease Association

Announcement from Mt. Diablo Parkinson's Network

## Special Joint Meeting for all its 4 groups:

**Saturday, April 16,  
From 10 – 12 noon**

**Location:** Grace Presbyterian  
Church, 2100 Tice Valley Blvd.,  
Walnut Creek.

**Speaker:** Susan Heath, RN, MS,  
CNRN.

**Topic:** Non-Movement Aspects of  
Parkinson's Disease.

**\*\*\*Bring a dish to share for lunch\*\*\***

For more information, please  
call Margy Hansell at  
925.939.4210.



## Natural Help for Insomnia

*Dr. Carolyn DeMarco*

Getting a good night's sleep may be the most important thing you can do for your health. In the last 100 years, we have reduced our average hours of sleep by more than 20%. The cost of sleep disorders and sleep-related accidents adds up to billions of dollars a year.

### Simple Things That Help

1. Take a hot bath with Epsom salts at bedtime.
2. Avoid eating later than 6 PM.
3. Listen to a relaxation tape or calming music at bedtime.
4. No caffeine after noon.
5. Avoid taking B vitamins in the evening.

*Edited from ArtPress International, 1998 issue.  
Carolyn DeMarco is a GP specializing in women's  
health and author of "Take Charge of Your Body."*

## Expert's Pain Prevention Checklist

Physiotherapist Karen Webb offers these tips to help prevent back, neck and other body pain:

### In Class or At Work:

- ✍✍ Maintain inward curve in lower back when sitting
- ✍✍ Interrupt long periods of sitting. Do five back bends every 60 minutes.
- ✍✍ Interrupt long periods of desk work. Do five chin tucks every 60 minutes.
- ✍✍ Interrupt standing bent forward. Do five back bends every 30 minutes.
- ✍✍ Interrupt typing. Stretch fingers, wrists, and shoulders every 60 minutes.
- ✍✍ Carry backpack on both shoulders and walk upright. If it's heavy, use chest and wrist or hip straps.
- ✍✍ Keep elbow slightly bent when carrying a bag.
- ✍✍ Stand tall when standing for long periods and occasionally shift weight from one foot to the other.
- ✍✍ When lifting, bend your knees, keep back straight, hold object close, and do not twist your body.

### At the Gym:

- ✍✍ Always warm up and cool down. Drink water.
- ✍✍ Use safe and effective equipment.
- ✍✍ Practice good form and technique.
- ✍✍ Do 10 "sloppy" pushups before and after each abdominal workout.
- ✍✍ Do five back bends after all strenuous workouts.
- ✍✍ Do five chin tucks when you feel a minor strain in your neck.
- ✍✍ When lifting, bend your knees, keep back straight, hold the weight close and don't twist the body.

### At Home:

- ✍✍ Use one pillow to sleep.
- ✍✍ Start and end your day with five "sloppy" pushups and five chin tucks.
- ✍✍ Be active every day.

*Adapted from Canadian Press. This article was forwarded by Betty Mak, of Toronto, Canada.*

## **Twice As Many Parkinson's Disease Patients Prefer Orally Dissolving Form of Carbidopa-Levodopa to Conventional Tablets**

Milwaukee, Feb. 14 /PRNewswire---  
A clinical study published in the January 2005 issue of "Clinical Therapeutics" showed that more than twice as many Parkinson's disease patients prefer Parcopa(TM)(carbidopa-levodopa orally disintegrating tablets) to conventional carbidopa-levodopa tablets. The primary factors influencing their preference were greater access to medication to treat "off" times, ease of performing daily activities, use for nighttime dosing and feeling less self-conscious about others noticing medication use. Parcopa is a unique formulation of carbidopa-levodopa that dissolves on the tongue without the need for water.

"Since Parkinson's disease patients experience symptoms such as tremors, rigidity and episodes of decreased movement or complete immobility, especially in the morning, compliance and access to medication can be a problem," said Michele Tagliati, MD, Director of the Parkinson's Disease Center at the Mount Sinai Medical Center in New York. "This study showed that Parcopa offers important benefits for many patients. Those who expressed a preference, preferred an orally dissolving tablet because they felt it was more convenient and easier to access -- which is particularly important for patients suffering from Parkinsonian symptoms."

### **Study Design and Results**

The multi-center, open-label, sequential study compared preferences for carbidopa-levodopa orally disintegrating tablets versus conventional tablets in 60 Parkinson's disease patients who had taken a stable dose of conventional carbidopa-levodopa for at least 30 days prior to the trial. Patients received conventional tablets for 7 +/- 3

days, followed by Parcopa for 14 +/- 3 days. During the last 3 days of each treatment period, they recorded their "on" and "off" times and medication use in a diary. On the last day of each treatment period, the Unified Parkinson's Disease Rating Scale (UPDRS) was administered. At the end of the study, patients completed a Global Preference Questionnaire (GPQ).

Nearly half (45%) of the study subjects preferred orally dissolving tablets, 35% had no preference and 20% preferred the conventional tablets. Factors cited as contributing to their preference for the orally dissolving formulation included:

### **Reasons Cited for Preference /Percentage of Patients**

Greater access to medication to treat "off" times: 50%

Easier to perform daily activities: 47%

Reduced concern about swallowing medication: 45%

Use for nighttime dosing: 42%

Less self-conscious about use in public: 42%

### **About Parcopa Recently approved by the FDA:**

Parcopa (carbidopa-levodopa orally disintegrating tablets) is a combination of carbidopa and levodopa in tablets that dissolve rapidly on the tongue, without the need for water. Parcopa's orally dissolving formulation is designed to provide Parkinson's disease patients with improved access to their medication. Parcopa is used to treat symptoms of Parkinson's disease, including tremors, stiffness and slowness of movement, and may permit the patient better mobility.

**“Parcopa....,” go to page 4**

### **“Parcopa....,” continued from page 3**

Parcopa is available in the same strengths and has the same dosage schedule as conventional Sinemet(R) (carbidopa-levodopa) tablets. The most common side effects include involuntary movements and nausea. Each 10mg/100mg tablet and each 25 mg/100 mg tablet contain phenylalanine 3.4 mg. Each 25mg/250 mg tablet contains phenylalanine 8.4 mg. For more information about Parcopa, talk to your healthcare provider or visit <http://www.Parcopa.com>.

*This article was forwarded by Linda Chen, a board member of PPSG. Linda is also a leader of the Palo Alto support group, in California. Thanks, Linda.*

### **Lee Silverman Voice Treatment (LSVT) at The Parkinson’s Institute**

**First effective treatment** established for treating voice and speech disorders in individuals with Parkinson’s disease and other neurological disorders.

Over 400 individuals with Parkinson’s disease have been treated with the LSVT in efficacy research studies.

The **LSVT improves both the voice and speech** of individuals with Parkinson’s disease by treating the underlying physical pathology associated with the disordered voice.

Treatment focuses on improving loudness and immediate carryover into daily communication enabling patients to **maintain and/or improve their oral communication.**

The **LSVT** is administered on an **intensive schedule** of 16 individual sessions in one month.

**90% of patients improve from pre-to post-treatment.**

Approximately 80% of patients maintain treatment improvements in their voice for 12-24 months post-treatment.

All patients report improvement in their ability to communicate.

**For More Information-  
Contact Randy Hoffman, MA CCC**

Speech & Language Pathologist – The  
Parkinson’s Institute  
408.734.2800 ext. 505

## **Drug May Cut Parkinson's Disease Disability**

**Downtime Shorter When Taking Rasagiline with Levodopa, Says Study.**

*By Miranda Hith, WebMD Medical News*

March 10, 2005 - An experimental drug called rasagiline may reduce disability in Parkinson’s disease patients.

That’s the indication of an international 18-week study funded by the drug’s maker, Teva Pharmaceutical Industries and H Lundbeck A/S. Rasagiline hasn’t been approved by the FDA for the treatment of Parkinson’s disease.

The drug is not a cure. Instead, it’s intended to help smooth out motor function problems that many Parkinson’s patients experience after taking the Parkinson’s drug levodopa for a long time.

"Most patients with established Parkinson's disease and sustained treatment with levodopa will eventually have motor fluctuations, defined as periods of the day with poor or absent motor function (off-time) alternating with periods of clearly improved motor function (on-time)," says a study in *The Lancet*.

*This article is forwarded by James McKarns, of San Mateo, California. Jim attends several local group*

#### **Disclaimer**

This document is published to promote a greater awareness of the problems caused by Parkinson’s disease. Neither the Parkinson’s Patients Support Groups, Inc., its members and employees, nor the individuals involved in its production make any warranty, express or implied, assume any liability or responsibility for accuracy, completeness, or usefulness of any information or represent that it will not infringe privately owned rights. Mention of any product, material, or service shall not, nor it is intended to, imply approval, disapproval, or fitness for any particular use.

*meetings and always shares his Parkinson’s research findings with others. Thanks, Jim!*



# ***Gene Therapy: A New Approach to the Treatment of Parkinson Patients with Response Fluctuations to Levodopa***

*By Michael Aminoff, M.D., D.Sc., Director, University of California-San Francisco Parkinson's Disease Clinic & Clinical Research Center, and Alvin Luk, Ph.D., Manager, Clinical Development & Operations, Avigen, Inc.*

## **Background**

Parkinson's disease (PD) is the second most common neurological disease after Alzheimer's disease, and is characterized by tremor, stiffness of the limbs and trunk, slowness of movement (bradykinesia), and postural abnormalities. About two in every 1,000 people in the general population have PD; this number is age-dependent so that among people aged 65 years and older, two per 100 have the disease. PD results from loss of, or damage to, cells in a section of the brain called the "substantia nigra." These lost or damaged brain cells are responsible for producing an enzyme, aromatic L-amino decarboxylase (AADC), which converts levodopa (the precursor of dopamine) to dopamine. Dopamine is needed for the normal control of movement. Patients usually seek medical help at a time in the course of the disease when an estimated 70 percent to 80 percent of these dopamine-producing brain cells have died.

Current drug therapy is focused on providing symptomatic improvement of the Parkinsonism and involves treatment with levodopa, dopamine agonists (e.g., pramipexole or ropinirole), amantidine and



anticholinergic agents. Dopaminergic therapy is often combined with catechol-O-methyltransferase (COMT) inhibitors (such as entacapone) and monoamine oxidase (MAO) inhibitors (such as eldepryl) to prolong the benefits of treatment. Doses are adjusted to obtain the best relief of symptoms while minimizing side effects. Levodopa is the most common and most effective therapy. It crosses the blood-brain barrier and is converted by the enzyme aromatic L-amino acid decarboxylase (AADC) to dopamine. With disease progression, levels of this enzyme decline, and conversion of levodopa into dopamine becomes less effective. In consequence, larger doses and more frequent intake of levodopa are required for satisfactory clinical response, and such dose escalations eventually become limited by the development of dyskinesias (which have an incidence of up to 80 percent after five years) and other behavioral and autonomic symptoms. At this stage, patients with PD have limited non-invasive treatment options, and the quality of life may become significantly diminished. A surgical approach that involves implantation of a device to allow deep brain stimulation may markedly reduce certain symptoms, such as uncontrollable dyskinesias or marked response fluctuations.

## **Gene Therapy**

In March 24, 2003, Mr. Tim Friend wrote in USA Today, "the concept for gene therapy is elegantly and deceptively simple: Replace a defective gene with a healthy one and cure a disease." The insertion of genes into cells will produce specific proteins that produce biological effects. The major challenge has been to deliver the selected genes to the appropriate target tissues. For this purpose, modified viruses have been adapted to carry the genes, as viruses are very effective at inserting their genetic material into cells. Gene therapy is a new and novel method for the treatment of certain neurological disorders. Considerable interest has focused on the possibility of using viral vectors to

deliver genes to the central nervous system. A common vector is derived from the adeno-associated virus (AAV), a virus that normally infects about 80 percent of the population during childhood but causes no disease. As a gene-transfer vector that lacks any disease associated with the original virus, AAV has the advantages that it transfects non-dividing cells such as brain cells and produces stable, prolonged expression of transgene. Because AAV is derived from a virus that is not a human pathogen, it is expected to induce only a minimal immune response when used in humans.

### PD and Gene Therapy



Although the etiology of Parkinson's disease is not well understood, it is a good candidate for gene transfer using AAV vectors for

several reasons. First, the pathology in early PD is limited to dopamine-producing cells in the substantia nigra, so that localized gene delivery is a viable therapeutic strategy. Second, the dopamine deficits and the functional consequences of dopamine-producing cell loss are well understood; hence, delivery of transgenes encoding enzymes involved in dopamine synthesis enhances dopamine production in the brain region that governs movement.

#### Gene Transfer in Animals

Animal models play a critical role in our understanding of the cause of human diseases and provide an opportunity to evaluate new therapeutic treatments. The reduction in AADC due to the loss of brain cells probably contributes to the loss of therapeutic efficacy of levodopa. This suggests that restoring AADC activity might result in a therapeutic gain. In animal studies, AAV vectors can be delivered to specific regions of the brain through

stereotactic injection. Animal studies of human AADC delivered by AAV have been performed in rats and monkeys and have demonstrated effective and robust gene transfer. Furthermore, studies of animals with experimentally induced parkinsonism have shown that combining AADC gene transfer and levodopa reduces the levodopa/carbidopa (Sinemet) requirement, thus providing a better clinical response with fewer side effects. To date, over 30 parkinsonian monkeys have been treated with this therapy; some have been followed for over five years by Dr. Krystof Bankiewicz (Professor of Neurosurgery at UCSF) after gene transfer and have shown continuing clinical benefit. Gene therapy is a new medical technique being used in a number of clinical studies for a number of different diseases. Experience with delivery of therapeutic genes into the brains of humans by means of AAV vectors is an emerging field. The most advanced human trial using AAV is a Phase 1 (safety trial) for the treatment of another disorder called Canavan disease. This study involves the delivery of an AAV vector into the brain of children with that disease. In September 2004, a Phase I clinical study was initiated of a novel gene therapy product that involves delivery of nerve growth factor (NGF) genes through an AAV vector delivery system for the treatment of Alzheimer's disease. Another study in Phase I trials involves an AAV vector containing a different enzyme, glutamic acid decarboxylase (GAD), to treat Parkinson's disease. Patients in that study are individuals who are already undergoing surgery for insertion of a deep brain stimulator (DBS). The efficacy of the gene transfer treatment will be determined during a delay in activation of the DBS. Since delivery of the vector is by stereotactic injection into the brain, there are strong parallels with the AADC trial now starting at UCSF and discussed in the next section. To date, no safety concerns have developed in either of these clinical trials, and the procedures are well tolerated.

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### Gene Therapy Trial with AADC

Building upon a number of animal studies of gene therapy for PD, a gene therapy clinical trial approved by the U.S. Food and Drug Administration and using AAV-containing normal human enzyme AADC (AAV-hAADC), has begun at the University of California San Francisco (UCSF), and patients with PD are being recruited to participate. This trial is a dose-escalation study to assess the safety of AAV-hAADC infused into the brains of humans with PD. The trial will also assess whether increasing the levels of AADC enhances the clinical effectiveness of levodopa, reducing dose requirements and thus the side effects associated with escalating levodopa therapy. Other objectives include determining a dose of AAV-hAADC that restores normal levels of AADC activity in the brain as determined by positron emission tomography (PET) scans, assessments of the effects of AAV-hAADC on clinical symptoms of PD, and assessment of the increase or reduction of oral levodopa that is taken by patients. In all, 15 patients with PD, who are candidates for surgical deep brain stimulation, will be selected by standard criteria. Three groups of patients will receive different doses of AAV-hAADC (five patients per group). Since the most important parameter to assess is the safety of this procedure and gene, further clinical trials with larger numbers of patients will be needed to better analyze the therapeutic benefits of AADC gene delivery once its safety has been confirmed. This gene therapy trial represents the first clinical use of AAV containing human AADC in the human brain.

For more information about this trial, please contact the authors: Dr. Aminoff at UCSF (Tel: 415-476-0947) or Dr. Luk at Avigen (Tel: 877-428-4436); or email [clinicaltrials@avigen.com](mailto:clinicaltrials@avigen.com).

*This article was forwarded by Linda Chen. Linda is a PPSG board member and the leader of Palo Alto Support Group, in California. Thanks, Linda!*

## Gait and Balance Classes Are Back!

- ✍️ **Marilyn Basham**, Physical Therapist, who was with the Parkinson’s Institute for four years and now returns, will teach classes.
- ✍️ Class meets most every Wednesday (call at the beginning of the month to check on dates).
- ✍️ **Beg/Int:** 10:30 AM-12:00 noon; for people new to the Institute, new to the diagnosis of a movement disorder, or who need assistance from caregiver to stand or walk.
- ✍️ **Advanced:** 12:30-2:00 PM; for students able to get down on the floor independently for gentle yoga or who would benefit from advanced gait activities.
- ✍️ \$10.00 donation per class (more if you wish). Classes are one-and-a-half hours. Caregivers are welcome, no charge. Participant must be accompanied by a caregiver if physical assistance is needed to participate.
- ✍️ Each participant sets his/her own pace. Exercises are done sitting and standing. Chairs are provided for those who need support to stand while exercising in the class. Besides exercises, there will be a lecture/discussion about some aspect of living with a movement disorder.
- ✍️ Register by calling the Parkinson’s Institute, at **408.734.2800**, and talk to Gloria.
- ✍️ It is necessary to register for classes prior to participation. You must have discussed your participation in the classes with your doctor if you have questions. For the first session we ask that you show up at least 15 minutes early to sign waiver and

complete medical history questionnaire.

## Parkinson's Hope Over "Glasses"

*A pair of glasses which use virtual imagery could help people with Parkinson's disease cope with walking problems, scientists say.*

The device uses light to project images in front of the user, helping them to focus and control their movement.

Researchers at Oxford Computer Consultants are now putting the headset forward for clinical trials.

Many people with Parkinson's have mobility problems but only one in 20 will benefit from the headsets.

People with Parkinson's, a degenerative brain disease which affects 3% of people over 75, do not produce enough dopamine - a chemical messenger responsible for allowing humans to control their movement.

Some people with the disease suffer from freezing, which renders them unable to move once they stop.

The headset, which could cost £1,400, works by producing visual clues - an accepted method of combating freezing.

People with Parkinson's who freeze can be prompted to start walking again if objects are placed in their way and they have to walk round them.

Lights from the headset create a tunnel-effect, which enabled users in the initial testing stage to focus on the virtual imagery and move more freely.

### Quality of life

Project co-ordinator Reynold Greenlaw said: "This is a major achievement, especially

when you take into account that falling is the second greatest cause of death in people with Parkinson's disease."

"It has an enormous effect on their quality of life and does not rely on any drugs or surgery."

Peter Walters, of the EU research and technology team which is helping to fund the project, said the headsets had the potential to "improve the quality of life" of many people.

"This is another example of how technology is being developed into applications that reach way beyond what are considered the normal boundaries of computer buffs."

And Robert Medowcroft, director of policy at the Parkinson's Disease Society, said the headsets were "encouraging".

"Those people with the condition who experience problems with 'freezing' and then starting to walk may find this device to be very helpful."

"It has been known for some time that visual cues can assist in overcoming these distressing problems and this innovative use of technology may provide a novel solution."

*Story from BBC NEWS:*

*<http://news.bbc.co.uk/go/pr/fr//2/hi/health/4299143.stm>. Published: 2005/02/27 00:52:46*

*GMT. This article was forwarded by Jim McKarns, of San Mateo, California. Thanks, Jim!*

***This newsletter was assembled by  
The Morgan Center in Santa  
Clara, California. Thank You!***

**If you have any items for sale or donation, such as exercise equipment, wheelchairs, etc., please write to PPSG, call us at 408-734-1593, or e-mail [ppsginfo@yahoo.com](mailto:ppsginfo@yahoo.com).**

## Upcoming Support Group Leaders Meetings

*By Charmaine Eng, Vice Chair, PPSG*

PPSG will soon be conducting the 2<sup>nd</sup> annual Regional Support Group Leaders Meetings on the following dates:

**April 22 (South Bay)** in Hollister; host, John Skinner; facilitator, Elliot Schrier.

*New Date!!!*

**April 18 (Peninsula)** in Millbrae; host, Leon Rosenthal; facilitator, Dave Russell.

**April 26 (North East Bay)** in Oakland; host, Robert Lemon; facilitator, Charmaine Eng.

At the meetings, the leaders will have the opportunity to discuss and share mutual problems, needs, and experiences and particularly to enhance resources they gather to conduct their support group meetings. The meetings were well attended last year, and we look forward to meeting again.

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### Some Local Support Group Activities:

#### Fremont

Our speaker at the February meeting was Ruth Narayan, PHN, of Human Services Department, City of Fremont. She explained to us what we were doing right and wrong concerning our eating habits and was very informative in doing so. We appreciate her taking time to address our group.

Our March 28 meeting was quite different from our regular meeting. We joined with the City of Fremont's Caregivers Support Program for dinner and entertainment. The Fremont Support Group meetings are held on the **4<sup>th</sup> Monday** of the month, at **7:00 PM**, at the Fremont Senior Center, 40086 Paseo Padre Parkway, Fremont. For questions, please call **Lettie Webb** at **510.656.6393** or **Bob Coon** at **510.794.7988**.

#### Hollister

We welcome all Parkinson's patients and their caregivers. Everyone who is interested is invited to attend our meetings. No reservations are necessary, just come!

Our March 1 speaker was Celia Bruneau, who is associated with attorney Don Branner in Salinas. Her topic was "Elder Law."

The Hollister Support Group meets on the **1st Tuesday** of every month, from **1:30 to 3:30 PM**, at First Presbyterian Church, 2066 Cienega Road, Hollister. Please contact **John Skinner** at **831.637.6755**, or **Shirley Kennedy** at **831.637.3839**.

#### Magnolia-Peninsula

##### Thursday, April 14

Hazel Horsnell and some of her colleagues will demonstrate various methods of Massage Therapy. This will be a unique "hands-on" session.

All meetings are held in the main conference room of the Magnolia Apartments, located at 201 Chadbourne Avenue in Millbrae. The Magnolia occupies a square block, bounded by Millbrae and Magnolia Avenues, as well as Chadbourne.

The meetings take place on the **2<sup>nd</sup> Thursday** of each month (unless otherwise

noted), at **1:30** in the afternoon. The sessions are free of charge and open to the public.

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Light refreshments are available after the meetings are adjourned. For information about the meetings, please call **Leon Rosenthal** at **650.348.3480**.

## Marin County

April's presenter: Kathy Quain, music therapist.

May's presenter: Paul Lofholm from Ross Valley Pharmacy.

The Marin Parkinson's Support Group meets on the **4<sup>th</sup> Tuesday** of most months, from **2 to 4 PM**, at The Redwoods auditorium, 40 Camino Alto, Mill Valley. The telephone number for The Redwoods is 415.383.2741. For information about the meeting, please contact **Gloria Rashti**, at **415.381.6680**.

## Oakland

In the April 7 meeting we dealt with 'End-of- Life Decisions.' The day started with music from a string quartet of antique viols, and continued with a short video about ending one's life. Then followed a presentation of various forms, guiding caregivers about one's choices (Advance Directives and Durable Power of Attorney).

In our May 5 meeting we will celebrate our long-term supportive connection with Bay Area Easter Seals.

The Oakland Support Group meets on the **1<sup>st</sup> Thursday** of the month, from **1:30 to 3:30 PM** at the Easter Seals Bay Area, 180 Grand Avenue, Suite 300, Oakland. For further information, please call **Robert Lemon**, at **510.526.2078**.

## Redwood City

Kaiser Redwood City Neurology Department's Jeff Javerbaum, M.D., joined us at our April 15 meeting. Special thanks again to Dr. B. Votteri of the Sequoia Hospital's Sleep Disorder Center, who spoke at our March meeting. Our one pound gift box of assorted See's candy is really working and attracting outstanding speakers! First it was Tracy Stewart, RN, in January, followed by Marilyn Basham in February (both of the Parkinson's Institute, clinical trials and physical therapy, respectively), followed by Dr. Votteri in March. Our April speaker was Dr. Javerbaum.

We have a special guest in May, Captain Bridget Lott of the California Highway Patrol. Capt. Lott heads up the CHP's Redwood City office. Bring your driving questions and concerns. You will find her to be a very special person!

**Remember our new time: 1:00 – 2:30 PM.**

PPAP-Positive People Against Parkinson's-meets on the **3<sup>rd</sup> Friday** of each month, from **1:00 to 2:30 PM (new time)**, at Sequoia Health and Wellness Center, 702 Marshall Street, Redwood City. Parking available in the rear. For more information, call **Sequoia Center** at **650.367.5998**. **Tom Constantino** and **David Shein** co-chair the meetings.

### MAILING LIST

If you would like to be removed from our mailing list or know someone who would like to be included, please take a minute, call us at **408.734.1593**, or e-mail **[ppsginfo@yahoo.com](mailto:ppsginfo@yahoo.com)**, and let us know.

## San Francisco

**Next Meeting: April 21st**

**5:30pm-7:00pm**

**Holiday Inn Chinatown**

(Corner of Washington & Kearny)

**Hotel parking free for this meeting!**

**Speaker: Carolyn Noble**

**Community Relations Director**

**Community Adult Day Care Center at St. Peter's**

Please call 415.352.6514, and ask for Tom.

The San Francisco group meets on the **3<sup>rd</sup> Thursday** of the month, at Holiday Inn Chinatown, corner of Washington & Kearny. For meeting time, call **Tom O'Brien** at **415.352.6514**.

## Vallejo

At our August meeting we had a luncheon. We purchased deli trays and had our luncheon in our meeting room. It worked out great!

At our September meeting we had Teresa Tempkin, RNC, MSN, ANP, from the Neurology Department at UC Davis Medical Center in Sacramento as our speaker. She presented us with information and some hope for the future that was beneficial to all of us.

At our October meeting we had the caregivers in one group and the Parkinsonians in another group. There was a lot of discussion in both groups that was shared by the members, especially the caregivers.

The group meets on the **3<sup>rd</sup> Monday** of the month, **except January and February**, when we meet on the **2<sup>nd</sup> Monday**. The meetings start at **2PM**, at the Kaiser Medical Center, 975 Sereno Drive, Vallejo. For meeting information, please call **Evelyn Fox** at **707.644.3390**.

## Forming New Support Groups

The following individuals are forming new support groups in their areas:

### **Corte Madera Region:**

Contact Diana Dunlap, Director of Health Services, at 555 Paradise Drive, Corte Madera, CA 94925, at 415.927.4200.

### **Merced Region:**

Contact Tony Gaestal, at 209.723.4616.

### **San Jose – South Region (Almaden – Blossom Valley)**

Contact Betty Havens at 408.269.2167

## Sloppy Joes

*By Trudy Grossman*



1 ½ lbs. ground beef  
1 small onion, chopped  
1 can tomato soup  
1 can tomato paste  
1 tbsp. vinegar  
1 tbsp. (packed) brown sugar  
1 tsp. dry mustard  
Salt and pepper to taste

Brown beef and onion in skillet on top of stove. Pour off fat. Put browned beef and onion in a casserole, and add the rest of ingredients. Bake for 45 minutes in a 325 ° oven.

*Trudy and her husband, George, were members of the Sunnyvale support group. Trudy and Phyllis Ng are also fellow members of the AAUW (American*

## **Betty Havens**

My name is Betty Havens and I seem to be a native Californian as I've been here from Colorado since 1946. I married Jerry Havens in 1976 and we have had a wonderful life with our extended family of 4 children and 6 grandchildren.

My first introduction to Parkinson's disease was in 1990 when the first of Jerry's symptoms appeared. We learned about the disease and what to expect as it progressed. This disease affects each person differently and Jerry's symptoms were always mild. As Dr. Tetrud at the Parkinson's Institute said, "If I didn't have your chart in front of me, I wouldn't know you had Parkinson's."

Soon after his diagnosis, Jerry enrolled in the Parkinson's Exercise Class at Hogue Center, and we attended faithfully. The caregivers would meet and discuss different problems that came up. It soon became apparent that we needed a place where we could all meet together.

Jerry and I were able to get permission to use the facilities at our church in San Jose, St. Francis Episcopal. So we had our first meeting in 1993 and officially became the San Jose Parkinson's Support Group. He and I thoroughly enjoyed meeting all the wonderful people who came looking for support, encouragement, and help.

Jerry had a series of terrible cancers from 1983 until 1998 – pancreatic cancer and bile duct cancer which needed NO chemo or radiation, and the third cancer under his liver. The doctor said, "I rebuilt him twice and I had nothing left to work with." Jerry died of a massive heart attack. He was only 71 – too young to die.

Because these people are such good friends and they need help, I decided to keep my position as facilitator. It is a very important part of my life and I don't want to give it up.

*Betty Havens is the leader of both San Jose– Willow Glen and the newly formed San Jose – Almaden/Blossom Valley Support Groups. Betty has made significant contributions to the Parkinson's community and her continuing support is greatly appreciated! Thanks so much, Betty!*

## **Allan Daily**

I was born and raised in Oakland, CA. I received my degree in Business Administration at U.C. Berkeley. I served 22 months in the army, 10 months in Korea. I have been married to Mary for 53 years. We have three sons, and they are all married and living in the greater S.F. Bay Area. I worked primarily in accounting for 32 years with Container Corp. of America in paperboard packaging. I worked the last nine years as an accountant with the City of Milpitas. I was retired in 1995. I was a board member of Second Harvest Food Bank for six years. I was the treasurer for the Friends of the Reading Program of the Santa Clara County Library for nine years. I was also the treasurer of St. Mark's Episcopal Church, Santa Clara, for seven years. I like to work at gardening and enjoy bridge.

*Allan Daily was recently nominated and approved by the Board of PPSG as a new board member. Allan and his wife, Mary, both attend the same church as Charmaine Eng, Vice Chair of PPSG, St. Francis Episcopal Church, in San Jose, California. Congratulations and welcome, Allan!*

**Volunteers –  
the Heart of the Community!**

## **My Experience with Pain**

*By Wanda Iverson*

Pain: We all experience it in life. However, what happens when it goes on day after day?

Three years ago, I had back surgery (crushed disc and bone spur). After that, my experience with excruciating pain started. During the first few weeks after the surgery, the staff informed me that the pain would eventually go away. However, physical therapy and medications were prescribed, with no results.

Finally, I was referred by the surgeon to the Stanford Pain Clinic. This has been my salvation!

I find the doctors and nurses to not only exercise their professional expertise but compassion and also understanding, and yes, I have relief from pain. Bless them.

During their recent phone conversation, Phyllis Ng learned about the procedures Wanda had undergone to help to reduce the prolonged pain she has endured, so she encouraged Wanda to write an article about this experience as therapy. Wanda always enlightens us with her spirit and positive outlook. Wanda is also a volunteer with PPSG. Thanks so much, Wanda!

## **Items to Give Away**

The following items are available to give away: walkers (2), bathroom benches (2), wheelchair (1), and commode (1). Please call Kay at 408.779.2298.

## **In Honor**

PPSG recently received gift donations in honor of the following individuals: Ray Beccio, Ronald Freeze, Frank Gomez, Stan Kuhl, Benjamin Nelson, Mr. and Mrs. Ron Trowse, and Mrs. Kathy Warthan.

## **In Memory**

PPSG recently received gift donations in memory of the following individuals: Meredith Bennet, Norma Binsacca, Don Bratrude, Dr. Michael Cahn, George Cechmanek, John W. Craig, James Duffey, Jeannette Evelyn, Jerrold Frye, Takashi Fukuchi, Virgil Greenley, George Grossman, Harry Guillot, Lawrence and Jewel Hall, Lillian Harris, Jack Hiyashi, Jane Hollingworth, Robert Holtzapple, Grace Italia, Kay Iwasaki, Pauline Johnson, Mary Kloock, Paul Kryoka, Dave Lorentson, E.A. Macomber, Albert Maurer, Margaret McGuire, J. Russell McKarns, Mary Nederostek, Donald Nelson, Florence Neri, Douglas Jerome Peterson, Anthony Ponza, Alice Roberts, Alice Ann Roberts, Jerry Swezea, Duane Voight, Bob Widger, and Violet Wong.

### **Thank you so much for your donations!**

Please use return address labels, to help us acknowledge your donations properly. Your generous contributions go to support newsletters, education and community awareness of Parkinson's disease.