

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

April/May 2006

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## 5/18, Patient-Caregiver Symposium

The Parkinson's Institute and the Neuroscience Institute at Stanford present "*Help for Today, Hope for Tomorrow*," an Annual Outreach Symposium for Parkinson's patients and caregivers. This year's event will be held at the Santa Clara Marriott hotel on May 18<sup>th</sup>, 2006, from 8:30 a.m. to 4:00 p.m. Together, The Institute and members of the NIS will provide a full-day symposium to include a morning seminar, including a distinguished panel of world-class physicians, epidemiologists, neurologists, clinicians and researchers. The symposium will provide an opportunity for attendees to ask questions of our panelists while enjoying a served lunch. In the afternoon, there will be 5 different break-out sessions offered to include speech therapy lessons, physical therapy, sleep disorders and a course in living a healthy lifestyle with proper diet. The day also includes a health fair, where attendees can learn about new treatments for PD, find support group information and enjoy artwork created by The Institute's Parkinson's patients.

For more information on this exciting event, and to print the registration form, please click here [Registration Brochure](#). For more information, you may contact **Debra Petersen** at (408) 542-5619. The website for The Parkinson's Institute is [www.theipi.org](http://www.theipi.org).

[Click here to see their press release.](#)

## 3<sup>rd</sup> Annual Parkinson's Walk In Sunnyvale

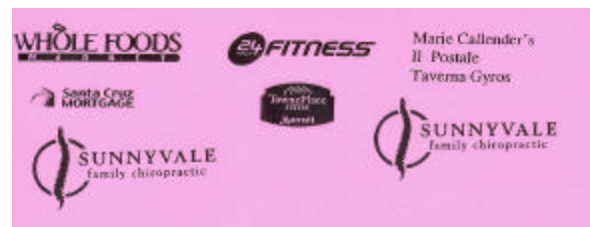
Saturday, May 13, 2006

*Fund the Research, Find the Cure*

Registration: 9 AM – meet at Washington Park in Sunnyvale (corner of Washington & Pastoria)

Walk begins: 10 AM. Total distance of walk: 1.8 miles or 4.2 miles.

For a walker registration form, go to [www.ppsg.org](http://www.ppsg.org)



## MJFF is assisting with the start-up of the CA PD Patient Registry

The Michael J. Fox Foundation for Parkinson's Research has announced a \$200,000 grant to help fund the pilot portion of the California Parkinson's Disease Patient Registry. A patient registry is a critical component of understanding the prevalence of this disease. California has collected data on a wide range of chemicals, and combining this data with PD incidence has the potential to link PD with environmental influences and toxic exposure. The Foundation joins The National Institutes of Environmental Health Sciences (NIEHS) in supporting this project.

Please visit <http://www.michaeljfox.org> for more info.

## **Preliminary Results Shows Creatine and Minocycline May Warrant Further Study in Parkinson's Disease: National Institute of Neurological Disorders and Stroke (NINDS)**

For release: Thursday, February 23, 2006

A National Institutes of Health-sponsored clinical trial with 200 Parkinson's disease patients has shown that creatine and minocycline may warrant further consideration for study in a large trial, according to Karl Kieburtz, M.D., M.P.H., University of Rochester, who spoke today at the World Parkinson Congress on behalf of the trial investigators. Study investigators caution that while the news is encouraging, the results do not demonstrate that these agents are effective in Parkinson's disease. Before these interventions can be recommended as a treatment they must be tested in a larger trial with hundreds of patients. Study findings are available online and will be published in the March 14 issue of *Neurology*.<sup>1</sup>

Parkinson's disease is a degenerative disorder of the brain in which patients may develop progressive tremor, slowness of movements, and stiffness of muscles. It affects approximately 1 percent of Americans over the age of 65. Although certain drugs, such as levodopa, can reduce the symptoms of Parkinson's, no treatment has been shown to slow the progressive deterioration in function.

The National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH) has organized a nationwide multi-center effort called NET-PD (Neuroprotection Exploratory Trials in Parkinson's Disease), a randomized, double-blind futility trial, to study compounds that may slow the clinical decline of Parkinson's disease. As the initial step in these efforts, creatine and the antibiotic minocycline were identified as agents worthy of preliminary study. Patients very early in the disease course who did not yet need medications typically used to treat their Parkinson's symptoms were included in the study.

"We are encouraged not only by these preliminary results, but also by the level of collaboration in the Parkinson's community. These findings represent the efforts of pharmacologists, clinicians, statisticians, and clinical trial experts - including NINDS staff - who have come together with academia, industry, patients, and foundation groups

to advance the development of innovative therapies for Parkinson's. The exceptional speed of patient recruitment allowed us to finish this study in record time," said Story Landis, Ph.D., NINDS director.

Patients were randomly assigned to receive minocycline, 200 mg per day; creatine, 10 grams per day; or placebo. The study participants were then followed for 12 months. Researchers examined the safety and tolerability of taking these medications as well as the severity of Parkinson's. Although neither agent caused major side effects, minocycline was not as well tolerated. Both creatine and minocycline appeared to modify the disease features as measured by a decline in the clinical signs of Parkinson's disease. However, it is important to note that the study was not designed nor intended to determine whether creatine or minocycline was effective as a treatment for Parkinson's. The study was primarily designed to determine whether it would be worthwhile to invest the resources necessary to determine if creatine and minocycline are effective treatments. Studies to determine the effectiveness of a drug typically require hundreds of patients followed for many years.

Based on the initial analyses of the pilot studies, creatine and minocycline have passed the first hurdle. Additionally, the NINDS has supported a pilot study of two other compounds, Coenzyme Q10 and GPI-1485, and the investigators are currently analyzing the data. The NINDS and the consortium are already planning a large long-term study of neuroprotection in Parkinson's disease.

The trial investigators note that while encouraging, this pilot study does not have sufficient numbers of patients or duration of follow-up to recommend that patients with Parkinson's take either agent. In fact, the investigators caution Parkinson's patients and their physicians not to interpret the results of this study as suggesting such a course of treatment. Further study is required before the researchers can conclude whether creatine or minocycline is in fact helpful, harmful or has no significant impact.

The NINDS is a component of the National Institutes of Health (NIH) in Bethesda, Maryland, and is the nation's primary supporter of biomedical research on the brain and nervous system. For more information, visit the NINDS website at

<http://www.ninds.nih.gov> or the NET-PD website,  
<http://www.parkinsontrial.org>.

<sup>1</sup> The NINDS NET-PD Investigators. "A randomized, double-blind, futility clinical trial of creatine and minocycline in early Parkinson disease." *Neurology*, March 14, 2006; 66: 664.

## Take the Park Out Of Parkinson's

*Elliot Schrier, Chair, PPSG*

In 2003, Jim "Parky" Wetherell of Hemet, CA, used his connections with the manufacturers to donate a recumbent tricycle to PPSG and The Parkinson's Institute for use in their outreach programs. We had met him while supporting his pedaling the San Francisco – Santa Cruz leg of the cross-country ride for Parkinson's. Since then, he has donated a trike to Power Over Parkinson's, a group at the University of Arizona, and is negotiating another donation with the University of California at Irvine's Parkinson's program. Dr. Jay Alberts, a Georgia Tech professor of applied physiology, is following indications that high-cadence pedaling can set back the Parkinson's clock

Parky's personal story has inspired Parkinson's patients from Australia to Wales. His message is straight forward: pedaling produces positive progress in Parkinson's patients. It is PPSG's uniquely active position within the Parkinson's community, with a Board of Directors composed of support group leaders, caregivers and patients, that enables it to find, relate to and support unusual outreach activities. In Parky's words:

"It is my opinion that there is not a better pill to take to curb anxiety and depression than to go for a brisk 10-20 mile ride. I started biking in 1981 and rode as much as my free time would allow. Over the years it got very painful in my neck and shoulders, and I was having difficulty drinking coffee in my right hand without spilling it. In 1995, I was diagnosed with Parkinson's disease.

"I tried everything I could think of to try to manage the pain so I could keep riding. As a do or die choice, I bought a recumbent *bicycle*. Because of my decreasing ability to balance on two wheels, in 1998 I traded it for a recumbent *tricycle*. With the trike I found my new life! It took me only 15 months to log my first 10,000 miles. In the past eight years I have ridden over 41,000 miles, much of it in special rides for Parkinson's awareness. For example, PPSG and TPI are sponsoring my participation in Iowa's RAGBRAI (Register's Annual Great Bicycle Ride Across Iowa) this July. Almost everything I wear has the word "Parkinson's" on it. You would be surprised at how many people I meet at bike

rallies just because of that word. Like Alan in Iowa (from Parky's unsolicited kudos):

Hi Parky-  
Met you when you stopped in front of my house to wait for the rest of the group to catch up during the last leg of Ragbrai.

That was no coincidence. Having been on the side-lines of a normal active life since 1995 due to a head injury which left my balance "off", I was pretty much convinced that there were no options for me other than to sit and watch the big dogs run by.

Then came Ragbrai and Parky just happens to stop 10 feet away from me on a slick rig which does not require staying on 2 wheels!

Thanks for not giving up...you might well have saved me. I will be in touch with questions about how to get started for sure.

Best wishes – Alan  
Clinton, Iowa

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Or Max in Australia:

G'day Parky,  
Last March I was diagnosed with advanced Follicular Lymphoma, an incurable type.  
This happened 2 weeks before departing for a bike tour of the USA that I had been planning for 3 years. Instead of riding across America I found myself in a city 600 Km from home with a Chemo drip in my arm.

Now, 11 months later and in remission for an indeterminate period, I am still going to go to Uncle Sam and attempt my ride even though I have days when I really can't do much. The whole idea scares the heck out of me sometimes but I refuse to sit around doing normal things waiting for the disease to return.

Reading your site and about the other people determined to have a life despite feeling miserable a lot of the time has really given me strength.

Thanks, Max.  
Australia.

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Or Sharon in Arizona:

Dear Parky,  
Here's evidence that your trike is being put to good use! I can't tell you how grateful I am. At this point, I ride every day and the trike is my only means of transportation. Everywhere I go your wonderful machine attracts attention. In fact, one day I heard footsteps beside me and looked up to find a former engineering student from the UA jogging beside me, enthralled. He had designed a similar trike for a special project but was fascinated at the way your machine solves some of the problems. He told me they had never been able to get

much speed out of their trike, which is a comfort to me since my average is 4 mph.

Last week we took the trike to the annual PD conference and I offered people rides. We had a steady stream of interested parkies. One man touched my heart--he moved with great difficulty and didn't speak at all but once we managed to get him seated and get his feet on the pedals - ---zoom. I think it was the first time in years he had any kind of mobility and he drove around and around with a smile on his face. I will be taking it to the walk-a-thon this weekend to try to convince some other parkies to try it.

Sharon  
Tucson

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Or Jan in Wales:

I have lived a highly adventurous life, physically as well as intellectually and celebrated my 60th birthday by jogging all the way to the summit of the highest mountain in Wales (just over 3000 ft). Then just before my 61st birthday, my first Parkinson symptoms appeared and I was formally diagnosed with PD in June 1998.

The miserable image of PD that was first presented to me shattered me and the so called wonder drug Ropinirole nearly destroyed me. I determined to take charge of my own recovery, using my own exercise system, but knowing what Jim was achieving gave me the will and confidence.

Within a few months, I was climbing mountains again. I haven't beaten Parkinson but I am living life to the full. Cycling, swimming, dancing, exploring rain forests, writing books, lecturing at conferences, creating works of art and so on.

I say, "Thanks a million, Jim" for flying the flag "I NEVER GIVE UP." If only more PD sufferers were to do a fraction of what you do, PD will soon lose its vicious teeth. Keep it up, Jim, and please keep inspiring us to live more. If I were a physician who had just diagnosed someone with PD, then the first thing I would prescribe is: GO TO JIM WETHERELL'S SITE AND GET THE RIGHT ATTITUDE. It is the most potent anti-oxidant that there is, and Jim will give to you a sack full completely free.

Dr.S.Jan.Abas School of Informatics  
University of Wales, Bangor, UK LL57 1UT

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Or Jay in Georgia:

Hi Jim,  
great website; your exploits are inspirational. I am a Parkinson's researcher and an avid cyclist so I have combined my two

loves and rode a tandem bike across Iowa last year with one of my Parkinson's patients.

The event was quite a success as we had numerous media outlets cover our story. As a result of the success and interest from Parkinson's patients in Atlanta I formed a non-profit, Pedaling for Parkinson's disease, to accommodate our needs and interests. We plan on doing the cross state tour of Iowa again this summer ([www.ragbrai.org](http://www.ragbrai.org)); I would like to invite you to join us in this trek across Iowa.

Feel free to give me a call some time to discuss possibilities. I think you epitomize the mission of our organization...maintain an active lifestyle and keep fighting the disease.

Best Regards.  
Jay L. Alberts, Ph.D.  
Applied Physiology

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"My website (with financial assistance from Charles Penninger) is [www.inevergiveup.org](http://www.inevergiveup.org). Many people are learning that a good way to treat a movement disorder is to keep moving. I consider my trike to be like a bridge that allows me to have a near normal life. TAKE THE PARK OUT OF PARKINSON'S."

(Parky will report on the week-long RAGBRAI in the winter quarterly. He will join TPI's exercise class under Marilyn Basham on May 17 and PPSG at its booth at TPI's May 18 seminar; stop by.)

## News from PPSG

**Dave Russell** recently left his post as the Treasurer to concentrate on his health. Dave will stay on the board to consult on financial issues. Thanks so much, Dave! We appreciate all your hard work!

**Allan Daily** was recently nominated and approved as our new Treasurer. Allan joined us last year and has contributed in many ways. Congratulations, Allan!

## 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**. Thank you!

### Calling All Runners/Walkers/Volunteers:

**Team Parkinson is once again an official charity of the San Francisco Marathon, taking place Sunday July 30<sup>th</sup>, 2006! Won't you join us?**

Formed in 2000, Team Parkinson is a non-profit organization whose staff and volunteers work year round to raise awareness regarding the impact of Parkinson's disease on society and to raise money to fund the scientific research required to find the cure.

We have focused on running events as our primary fundraising strategy. Individual runners and walkers choose to train and run/walk for Team Parkinson, and use the race as an opportunity to solicit donations from family and friends to support their efforts. Last summer, Team Parkinson was the top charity at the San Francisco Marathon, with 80 athletes registered over the four events, and over \$42,000 raised! We hope to build on that success this year! We welcome all those concerned with finding a cure—people living with Parkinson's, caregivers, family members and friends—to join us as a participant or volunteer. Under the guidance of The Parkinson Alliance, we guarantee that 100% of all net proceeds go directly to research.

**To Register with Team Parkinson for the San Francisco Marathon, go to the race website at: [www.causetorun.com](http://www.causetorun.com)**

**On the Entry Form, under "Cause Team #": Select TEAM #2 - TEAM PARKINSON**

**For more information contact:**

**SF/Bay Area Chair: Jennifer Bugnatto, at (415) 412-3038, [teamparkinsonsf@yahoo.com](mailto:teamparkinsonsf@yahoo.com)**

**Visit the Team Parkinson website: [www.teamparkinsonla.org](http://www.teamparkinsonla.org)**

*This newsletter was assembled by The Morgan Center. Thank You!*

## Atypical Parkinsonism Bay Area Caregivers

*(meets irregularly, please call)*

**3rd Sundays, 5:00 - 7:00 PM**

Mimi's Cafe

2208 Bridgepointe Parkway, San Mateo

**Robin Riddle - 650.233.9277**

**[E-mail:rriddle@stanfordalumni.org](mailto:rriddle@stanfordalumni.org)**

### Berkeley

The group meets on the **3<sup>rd</sup> Monday** of the month, at North Berkeley Senior Center, at 1901 Hearst Avenue (at Martin Luther King Way), Berkeley, and the meeting time is **10:00 AM-12:00 noon**.

For information, call **Roddy at 510.231.1998** or **Mitzi Cahn at 510.527.9075**

### Daly City

The Daly City Support Group meets on the **1<sup>st</sup> Tuesday** of the month, from **3:00 to 4:00 PM**, at Doelger Senior Center, 101 Lake Merced Blvd., Daly City. For support group information, please contact **Leonard Ke at 415.587.1285**.

### Fremont

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**.

### Fremont Caregivers

For information regarding the caregiver program in Fremont, please contact **Nancy Rothschild**, Caregiver Project Coordinator, at **510.574.2035**.

### Hollister

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 **Shirley Kennedy at 831.637.3839** or **John Skinner at 831.637.6755**.

### Los Altos - YPSG (Young Parkinson's Support Group)

Meets the **2nd Saturday** of each month from **10 AM- 12:00 noon** in the Live Oak Room of the United Methodist Church of Los Altos (Foothill

Expressway at Magdalena Avenue).  
Contact **Dean Prescott** at **408.738.2505**  
**deanp53@yahoo.com**, or **Dick Lacy** at  
**650.328.3429**.

## Magnolia-Peninsula

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, Magnolia, Chadbourne and Lewis Avenues.

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

## Marin County

March 28:  
2 pm *Chat Circles* - We were very fortunate to have therapist, Joann Katz, to come to our caregivers support session. Thank you, Joann.

We had John Argue at our Parkinson's patients session. Thank you, John, for more than a year of driving to Marin from the East Bay. We still have your program. Parkinsonians will gather to exercise.

3 pm: Rita Widegren on Project Independence 2006.

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**.

## Modesto (new group)

Modesto Parkinson's Support Group meets on the **3<sup>rd</sup> Wednesday**, from **1:30 - 3 PM**, at the Centenary United Methodist Church, The Fireside Room, at 1911 Toyon Avenue, Modesto, CA 95350, (Located at the corner of McHenry and Briggsmore Avenues).

Contact **David** and **JoAnn Ryan** at **209-529-5643** or **davejoann@sbcglobal.net**.

## Monterey

We meet in the S.H.A.R.E. Room, at Monterey Adult School, 200 Coe Ave., Seaside. The group meets on the **3<sup>rd</sup> Monday** of the month, from **2:30 to 4:00 PM**. For further information, please call **Kathy Warthan** at **831.372.7510** or **Helen Garrett** at **831.657.4241**.

## Mt. Diablo Parkinson's Network

**General Meetings:** the group has merged with Early Onset Support group, so there will be **NO MORE 2<sup>nd</sup> Monday meetings**. The group meets on **3<sup>rd</sup> Saturdays** from **10 AM-noon**. For meeting location, call **Nancy Walls** at **510.236.7065**, or **Philip Wheeler** at **510.527.3588**, or **Ronalee Spear** at **925.284.2189**.

**Caregivers Support Group:** Meets on **last Wednesdays** at **Jewel Wallach's** in Rossmoor, Walnut Creek. Call for information at **510.236.7065**.

**Pleasanton Tri-Valley Support Group:** Meets on **2<sup>nd</sup> Saturdays, 10 AM-noon**, at Senior Center, 5353 Sunol Blvd., Pleasanton. For information call **Cliff Terry** at **925.935.1772**.

## Oakland

*Taxi scrip is available! Contact Robert Lemon.*

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**.

## Palo Alto

The Palo Alto Support Group meetings are held on the **2<sup>nd</sup> Wednesday** of the month, from **2:00 to 3:30 PM**, at Avenidas (the Palo Alto Senior Center), in the dining room (La Comida), 450 Bryant Street, Palo Alto. For meeting information call **Linda Chen**, at **650.254.0906**. For directions, call **650.326.5362**.

## Petaluma (new group)

The group meets at Sunrise of Petaluma, at 815 Wood Sorrel Drive, Petaluma. Call **John Strong** at **706.763.3522** for meeting date and time.

**Treadmill Available! Like New!**  
**Call 408.356.5390**

## Redwood City

**Don't forget our new time: 1:00 – 2:30 PM**

At the March 17 meeting, we listened to Captain Bridget Lott, Head of the California Highway Patrol's Redwood City Office, for her informative talk on Safety and Older Drivers.

On April 21, we will be joined by everyone's favorite RN, the Parkinson's Institute's Tracy Stewart. She will review current clinical trials and new drugs expected to be out this year. We are looking for a May speaker.

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 Hospital's 4<sup>th</sup> Floor Roof Conference Room, 170 Alameda de Las Pulgas, corner of Alameda and Whipple, Redwood City. Valet parking is available.

For more information, call **Sequoia Center** at **650.367.5998**. **Tom Constantino** and **David Shein** co-chair the meetings and **Ray Lang** President Emeritus.

## Roseville

The group meets on the **1<sup>st</sup> Tuesday** of the month, from **1:30 to 3 pm**, at Roseville Maidu Community Center, at 1550 Maidu Drive, Roseville. Contact **Linda Krisa** at **916.261.1321**.

## Salinas

The Salinas Support Group meets every **4<sup>th</sup> Wednesday** of the month, from **2:00 to 3:30 PM**, at The Salinas Adult School, 20 Sherwood Place, Salinas. For further information, please call **Sherry Whitcomb (new leader)** at **831.663.5926**.

## San Jose – Berryessa

The group meets at Berryessa Community Center, 3050 Berryessa Road, San Jose, on the **1<sup>st</sup> Wednesday** of the month, from **1-2:30 PM**. Contact **Bob and Jane Pomeroy** at **408.263.8485**.

## San Jose – Willow Glen

We are now taken care of through June, then no meeting in July.

The San Jose Support Group met on March 3 with 35 people coming out in the cold, rainy weather. Our speaker was Professor Tony Fink from UC,

Santa Cruz. He presented a very interesting talk, with slides, on the basis of Parkinson's disease and some of the research being done. We had our usual "happy hour" with coffee, juice and delicious goodies from the Safeway store, thanks to Joe and Mary Ulloa who have been so faithful each month in getting and preparing our refreshments - many thanks!

The speaker for next month will be Dr. Simon Tan, a neuropsychologist at Stanford University Medical Center.

The San Jose Support Group meets on the **1<sup>st</sup> Friday** of the month at St. Francis Episcopal Church, 1205 Pine Avenue, San Jose, between **10:00 and 12 noon**. Please call **Betty Havens** at **408.269.2167**.

## San Jose Caregivers

The San Jose Caregivers Support Group usually meets on the **4<sup>th</sup> Wednesday** of the month, from **1:30 –3:30 PM**, at St. Francis Episcopal Church, 1205 Pine Avenue, San Jose. For information, please call **Charmaine Eng** at **408.723.8116**.

## San Leandro

The San Leandro group meets on the **1<sup>st</sup> Thursday** of the month, **except July and August**, at **10 AM**, at the Education Center of San Leandro Hospital, 13855 East 14<sup>th</sup> Street, San Leandro.

For questions please call **Norma Zeff** at **510.663.6435**, or **Harry Santi** at **510.351.3224**

## San Mateo Caregivers

The group meets on the **1<sup>st</sup> Wednesday** of the month, from **2:30 to 4:30 PM (new time)**, Ellsworth Room, 100 San Mateo Drive, San Mateo. Call **Carol Hoffman** at **Mills Health Center**, at **800.654.9966**.

## Santa Cruz

The Santa Cruz Support Group meets on the **1<sup>st</sup> Wednesday** of the month at St. Stephen's Lutheran Church, 2500 Soquel Avenue, Santa Cruz, from **12:30 to 2:00 PM**. For information, please call **David Donahoe** at **831.479.4485**.

## Saratoga

The Saratoga Support Group meets on the **3<sup>rd</sup> Tuesday** of the month at 19449 Via Real, Saratoga,

from **2:00 to 4:00 PM**. For information, please call **Lois McPherson** at **408.867.1807**.

### **Sonoma County**

The group meetings are held on the **1<sup>st</sup> Saturday** of each month, **except for the months of January, July, and September**, (due to national holidays which conflict with our dates). Meetings are held at the First Congregational Church, (UCC), at 2000 Humboldt Street, Santa Rosa. They begin promptly at **1:00 PM** and last about two hours. Excellent speakers represent a variety of resources important to the Parkinson's community.

Call **Ron and Colleen Trouse** at **707.526.4373** for more information. Parkinsonians and their guests, caregivers, or family members are encouraged to attend this meeting.

#### **Other Group Activities**

Satellite support groups meet at various locations throughout the area, meeting in members' homes. To find out about the availability of one of these groups, please call **Ron and Colleen Trouse** at **707.526.4373**.

### **Sunnyvale**

**May: Lisa St. John**, Clinic Manager of Hyperbarics Bay Area, will be our speaker. Her topic is "**Hyperbaric Oxygen Therapy.**" Special thanks to **Maxine Voight** who invited our speaker.

The Sunnyvale Support Group meets on the **2<sup>nd</sup> Wednesday** of the month between **1:00 and 3:00 PM** at the First United Methodist Church, 535 Old San Francisco Road, Sunnyvale. For information, call **Linda Filice** at **408.978.2859**, or **Phyllis and Henry Ng** at **408.733.5648**.

### **Tulare-Kings**

The Tulare-Kings group meets on the **1<sup>st</sup> Friday** of the month, at **10:30 AM**, at Visalia United Methodist Church, 5200 W. Caldwell Avenue, Visalia, CA 93277.

For more information, please contact Mary Dickerson, at **559.622.9044**, or the church office at **559.627.1660**.

### **Turlock (forming)**

Call **Donald Jackson**, at **209.606.9127**.

### **Vallejo**

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

### **YOPD**

The group meets in the Board Room of Lucile Packard Children's Hospital, at 725 Welch Road, Palo Alto, CA, on **2<sup>nd</sup> Tuesday** of every month, from **6:30 to 8 PM**. For information, please call **Bill Lev** at **831.662.3825**.

### **Ten Tips for Family Caregivers**

1. Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
2. Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
4. When people offer to help, **accept the offer** and suggest specific things that they can do.
5. **Educate yourself** about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
7. **Trust your instincts**. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to **dream new dreams**.
9. **Stand up for your rights** as a caregiver and a citizen.
10. **Seek support** from other caregivers. There is great strength in knowing you are not alone.

*Contributed by the National Family Caregivers Association.*

## Sleep Apnea is Linked to Altered Glucose Metabolism and May Lead to Type 2 Diabetes

Biotech Week via NewsEdge Corporation :

2005 DEC 14 - (NewsRx.com) -- Sleep apnea is independently linked to altered glucose metabolism and may lead to type 2 diabetes mellitus.

According to a review from Maryland, "Sleep is a complex behavioral state that occupies one-third of the human life span. Although viewed as a passive condition, sleep is a highly active and dynamic process. The sleep-related decrease in muscle tone is associated with an increase in resistance to airflow through the upper airway. Partial or complete collapse of the airway during sleep can lead to the occurrence of apneas and hypopneas during sleep that define the syndrome of sleep apnea."

N.M. Punjabi and V.Y. Polotsky from Johns Hopkins University remarked, "Sleep apnea has become pervasive in Western society, affecting similar to 5% of adults in industrialized countries. Given the pandemic of obesity, the prevalence of type 2 diabetes mellitus and metabolic syndrome has also increased dramatically over the last decade."

"Although the role of sleep apnea in cardiovascular disease is uncertain, there is a growing body of literature that implicates sleep apnea in the pathogenesis of altered glucose metabolism. Intermittent hypoxemia and sleep fragmentation in sleep apnea can trigger a cascade of pathophysiological events, including autonomic activation, alterations in neuroendocrine function, and release of potent proinflammatory mediators such as tumor necrosis factor-alpha and interleukin-6. Epidemiologic and experimental evidence linking sleep apnea and disorders of glucose metabolism is reviewed and discussed here."

"Although the cause- and-effect relationship remains to be determined, the available data suggest that sleep apnea is independently associated with altered glucose metabolism and may predispose to the eventual development of type 2 diabetes mellitus," concluded the authors.

Punjabi and Polotsky published their review in the Journal of Applied Physiology (Disorders of glucose metabolism in sleep apnea. J Appl Physiol, 2005;99(5):1998-2007).

*Visit the PPSG Website*

[www.ppsg.org](http://www.ppsg.org)

## Help Prevent Home Break-Ins While You're Away

Planning a vacation or traveling on business? Whether you're going away for two days or two months, here are some simple safety tips to consider to help protect your property:

- ?? Don't hide spare keys – give them to a relative or trusted neighbor who can keep an eye on your home while you're gone.
- ?? Lock all doors and windows, even those in out-of-the-way spots.
- ?? Have your local post office hold your mail.
- ?? Use automatic timers to turn indoor lights on and off.

## Putting Cell Phone on ICE Could Help Save Your Life

In a medical emergency, saving time could help save your life. So consider programming the listing "ICE" (short for "In Case Of Emergency") into your cell phone's address book, followed by the name and phone numbers of one or more emergency contact partners.

You will help paramedics, police, and firefighters get the vital information they need if you require immediate medical attention. Your ICE partner(s) should:

- ?? Have a list of people to contact on your behalf.
- ?? Be aware of any medical conditions that could affect your treatment.
- ?? Choose an immediate family member authorized to make decisions on your behalf, if you're under 18.

*Source: Tips from Allstate Insurance; forwarded by Charmaine Eng. Thanks, Charmaine!*

## PPSG Board Meetings

We welcome anyone to drop by our board meetings and share ideas with us! We meet on the **3rd Monday** of the month between **1:30 and 3:30 PM** at the Parkinson's Institute. To confirm meeting dates and time, please call us at 408.734.1593.

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