

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

*Fall Quarterly 2005*

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## **Where to Live- A Housing Guide for Older Adults**

The 12<sup>th</sup> edition of *Where to Live, A Housing Guide for Older Adults*, is hot off the presses. Published by Avenidas since 1976, this guide simplifies the maze of independent and assisted living housing alternatives in Santa Clara and San Mateo counties.

Researched and newly updated by Avenidas staff, the publication simplifies the range of housing options, including subsidized and below market rate independent housing, market rate independent and assisted living facilities, residences geared towards individuals with Alzheimer's disease or dementia, retirement community residences to purchase and continuing care retirement communities.

Guidelines include choosing residential care facilities and skilled nursing facilities, as well as important information on alternatives to moving, home sharing, and adult day health centers.

The information and referral section has been expanded, a new glossary has been included, and websites to many valuable resources have been added throughout this edition. *Where to Live* is available at Avenidas for \$7.50, and can be mailed for an additional fee of \$2.50 per copy. Call 650.289.5400, and speak with Helen Landsman or Shirley Lowler, Avenidas Certified Information and Referral Specialists.

Avenidas is a private, non-profit agency celebrating over 35 years of helping mid-Peninsula seniors live well, learn, and maintain their independence.

Avenidas serves seniors and caregivers in the communities of Palo Alto, Stanford, Menlo Park, Los Altos, Los Altos Hills, Mountain View, East Palo Alto, Atherton, Portola Valley, Redwood City and Woodside. Avenidas SeniorCare also assists caregivers from elsewhere whose parents or loved ones live in the mid-Peninsula. Avenidas is located at 450 Bryant Street, Palo Alto, CA 94301

*This information was forwarded by Marge Shively.  
Thanks so much, Marge*

## Dinner with Davis Phinney

By Leonard Ke  
Daly City Support Group Leader

One thing about having Parkinson's, or other chronic disabling diseases, is you have to find ways to remain positive, to appreciate what you have, and to take part in shaping your own destiny. Having America's winningest cyclist as an inspiration really helps create these attitudes.

Davis Phinney was the first American to win a road stage in the Tour de France (1986). He followed that up with another stage win (1987). He won the prestigious US Professional National Road Championship in 1991. He won national and international individual and team titles. His powerful sprint catapulted him around his competitors to the finish line so often and so predictably that he was dubbed "The Cash Register."

In 2000, he was diagnosed with Parkinson's. Davis was only 40 years old, led a healthy lifestyle, and was a world-class athlete. Like many of us, he wondered why and how he got this disease. He continued to lead cycling tours in Italy (with his wife, Connie Carpenter, a former Women's World Cycling Champion, and their two children, Kelsey and Taylor). He also held multiple positions with cycling related businesses and organizations. He also started the Davis Phinney Foundation (see [www.davisphinneyfoundation.com](http://www.davisphinneyfoundation.com)), to raise funding needed to find a cure for PD.

Which brings me to September 2, 2005...The Barclay's Global Investor's Grand Prix of San Francisco, America's toughest one day bike race was being held on September 4. This race, which is 110 miles long, and features 10 ascents of the Fillmore Street hill (22% grade) and 15 ascents of the Taylor Street hill (19% grade), brought in a large contingent of racers and their support. Davis arranged a dinner at the Italian Athletic Club in North Beach, which was immediately sold-out. Everyone who attended was treated to a night of fun as

Davis was roasted by a remarkable generation of US cyclists and San Francisco's own, Robin Williams. Williams had the best line of the evening: Noticing that Davis was drinking coffee during his performance, Williams said, "You must be crazy! A person with Parkinson's drinking coffee is like a hemophiliac juggling knives!"

And Bob Roll noted how life hasn't changed much from the years he raced. He said that he was staying at his mother's house, sleeping on the sofa. He mentioned the running conversation he has with his mom is about getting gas from eating bananas and peanut butter.

What I noticed was the camaraderie that exists in the cyclists, the result of having shared a unique experience in the sport of bicycle racing. I saw some friends I hadn't seen in ten years. They asked how I was doing and we relived many of the races we rode in against each other, although our memories changed the outcome of the race or speed of our bicycles.

Davis said that this event was so successful on very short notice that he plans to have another fund raising event next year. For which we can all be grateful.

*Merci*

**On October 21, PPSG is hosting a Volunteers Luncheon, to be held at Michael's Restaurant, in Mountain View, CA. Thank you so much for helping in the Parkinson's community!**

The Parkinson's network of Mt. Diablo is holding a symposium on **November 5th** at the Concord Hilton, in Concord, CA; several speakers who are well known in the Parkinson's community have consented to speak. For more information please call **Cliff Terry at 925-935-1772**

# My Approach to Parkinson's

By Dean Prescott

It's about a 60-mile bike ride from Los Gatos to Santa Cruz Beach and back, and I used to make the trip at least once and sometimes several times a year, usually with a friend. It was extremely dangerous riding up winding and crowded Highway 17 to the Old Santa Cruz Highway turnoff. For a short way, the road was so narrow that the white line marking the edge of the right lane was literally the edge of the road and we would ride right on that line. If you moved too far to the right, you would fall into the mountain that hugs the right side of the road, too far to the left and a car or truck coming around the turn from behind would not be able to avoid hitting you. The concentration and noise of the highway was contrasted by the peace and quiet that we experienced immediately after turning onto the Old Santa Cruz Highway and flying down the short hill that took us away from busy Highway 17.

The rest of the trip was scenic and calm, with usually just a few cars passing without incident. It was slow and steady up the hills and fast going down, and we came to know every hill and every turn on the route. There was an old grocery store at the top of the hill that was sort of the hub of the local community. We would stop for a drink and something to eat on the way over and on the way back and we would sit on an old wooden bench or read the bulletin board while we rested.

Then for some reason I stopped making the trip every year. It was two or three years before I made my next trip. I wasn't prepared for the changes I saw. The old store was gone and had been replaced by a new air-conditioned market with automatic doors that replaced the slamming screen door. The bulletin board and the bench were gone. I noticed other changes in the community. There were more homes and the homes were different. They had gates and alarms. The cars were new and shiny. Civilization had moved in. The old ride to

Santa Cruz was no longer that much different from the valley I was getting a break from.

There was one more important change and that was a change in me. I just didn't feel right. I wasn't any more tired than I would expect to be, but it seemed that the pedals weren't turning as they were supposed to.

I didn't know it then, but that was perhaps one of the early signs that Parkinson's disease was creeping into my life. That was the last time I rode my bike to Santa Cruz. Long distance cycling is one of the pleasures that Parkinson's disease has taken from me. Medication helps, and for several years it allowed me to continue working, but now it just gets harder and harder to find the right combination of drugs that will allow me to have a minimal level of function without excessive side effects such as dyskinesia.

When I was diagnosed with Parkinson's disease in 1995, I never asked "Why me?" I didn't question my doctor's judgment. There was neither anger nor indignation. My wife and I were, however, very worried. How much time did I have before I could no longer function? How would I support my family? Meeting people who had had PD for 10 and 20 years and were still getting along gave me encouragement. I started taking medication and was surprised at how much better I felt. Gradually I came to realize that it is possible to live with Parkinson's, even if I'd rather live without it.

My attitude is: "We've got it, let's make the best of it." I'm not able to enjoy participating in some of the activities I used to, but there are still a lot of things I can do. I'm going to focus on those things while I can.

*Dean Prescott is the leader of the Los Altos –YPSG (Young Parkinson's Support Group) as well as a member of the Sunnyvale support group. In June, Dean participated and helped at the Sunnyvale Parkinson's Walk event. Dean recently joined PPSG as a Board Member. Congratulations, and welcome, Dean!*

# Limericks in Honor of our Special iHop Waitress

*By Ron Trowse*

*Leader of Sonoma County's Parkinson's SG*

There once was a writer named Ron  
O'er whose limericks no editor would fawn  
"They're worth less," said the  
editor of the Parkinson's Newsletter,  
"Than the cheap paper he's written them  
on."

'Tis true they're a humble creation.  
My limericks shows little invention,  
I'll readily confess  
That, unlike DBS,  
They're just brainless de-stimulation.

The language of PD doesn't please us  
For lim'ricks need words more facetious  
For instance, we have thought  
That "The M. J. Fox Trot"  
Should replace that dull term "Dyskenesias."

Oh at ihop we've met kind Arlene  
Among waitresses we judge her the queen  
Though our tips are quite small  
She is attentive to all  
And these limericks she judges supreme.

At a truck stop where once worked Arlene,  
From the truckers she heard jokes obscene.  
But when we Parkinson blokes  
Urged her tell one of these jokes,  
She said, the ambiance at iHop's too  
pristine.

Our antics at iHop grow more manic  
The good management comes closer to  
panic,  
But if they charge us with  
offenses,  
We have the best of defenses:  
"Our behavior is just symptomatic."

Arlene's view of the limerick's so much  
better  
Than that of either Ihop or Newsletter  
She sees though it's rude

And admittedly crude  
It can be a grand facilitator.

This doggerel was intended to honor the  
waitress at the Santa Rosa International  
House of Pancakes who on alternate Fridays  
valiantly serves our raucous Parkinson  
Men's Breakfast group, part of the PD  
Support Group of Sonoma County. Arlene,  
who is very patient with all our foolery,  
responded to the limericks with her usual  
grace.

DBS refers to Deep Brain Stimulation, a  
surgical procedure involving the insertion of  
a wire or two into the skull and an electric  
box in the chest which sends stimulation via  
the wires. There's a wee bit more to it than  
this, but surely you get the idea. I haven't  
had the procedure (despite its obvious  
appeal).

The M.J. Fox, of course, is Michael J. Fox,  
the actor and fellow Parkinsonian.

## Men Are Caregivers, Too

**Almost half the people who care for an  
elderly, disabled, or chronically ill family  
member or friend are men. But the way  
they cope is different from the way  
women do.**

*By Richard Trubo  
WebMD Feature*

*Reviewed By Michael Smith*

Marty Beilin plays many roles in his day-to-  
day life -- from breadwinner to husband to  
father of two daughters. But for the past five  
years, he has also found himself thrust into a  
new and unanticipated role -- as primary  
caregiver for his wife, Debbie, who has  
multiple sclerosis.  
"It changed everything," says Marty, who  
teaches school in the Philadelphia area.  
"There's shock, denial, anger, guilt, and then  
finally acceptance."

Marty has assumed a long list of  
responsibilities in caring for his wife who  
must use a wheelchair or a motorized  
scooter when she leaves the house. "Debbie

has chronic, progressive MS, but luckily she has not been so impaired that I've had to stop working," says Beilin. "At this point, we try to live as normally as we can. The key is to find a way to be a caregiver, but also to go beyond just coping skills and to have a life."

According to the National Family Caregivers Association (NFCA), there are more than 54 million Americans like Beilin who have provided care for an elderly, disabled, or chronically ill family member or friend during the past year. Even though caregiving is often thought of as a role assumed primarily by women, an NFCA survey found that 44% of caregivers are men.

Beilin is president of the 14-year-old Well Spouse Foundation, which provides information and support for spousal caregivers. "There hasn't been enough attention to the needs of family caregivers," says Beilin. "People see the person in a wheelchair, but they don't really focus on the person *pushing* the wheelchair."

### **Rising to the Challenge**

Whether an ill relative has been diagnosed with Alzheimer's disease, Parkinson's disease, multiple sclerosis, Lou Gehrig's disease, or a stroke, male caregivers often find their new role to be daunting and all-consuming. Most men have grown up in a household -- and certainly a culture -- in which females have been perceived as the primary family nurturers. Yet often by necessity, more men than ever are rolling up their sleeves and helping an ill loved one with day-to-day tasks such as dressing, toileting, bathing, eating, changing dressings, and managing medications. Kathleen O'Brien, vice president of program services for the Alzheimer's Association, says that many men may not have the same comfort or confidence level as women in handling the tasks of caregiving. "Some have a particularly difficult time with the more intimate care, such as a son bathing and dressing his mother," she says.

To compound the stress in their lives, baby-boomer men may find themselves sandwiched between elder care and child care, and as they juggle work, family, and the needs of an aging parent, their stress and frustration can often turn into anger, despair, exhaustion, and burnout.

### **Finding Help**

In confronting the responsibilities before them, men are more likely than women to delegate some of the caregiving responsibilities to others -- either to other family members, or to outside help who they've hired to handle many of the home-care duties.

"Some men feel that they don't have to do it all on their own, and they're better than women at saying, 'I need some help with this -- you do this part, and I'll do that part,'" says Carole Cohen, MD, associate professor of psychiatry at the University of Toronto. "In the work world, they may have become accustomed to this kind of delegating, whereas women of the same generation may be less likely to feel that it's OK to get help." Gerontologist John Khajit, a family consultant with the Family Caregiver Alliance, agrees. "Men tend to approach caregiving a little differently than women, and are more likely to try to problem-solve the situation," he says. "They seem quicker to hire a home-care worker, to call social workers, and to contact local agencies. I've talked with men who want to move things forward, want to take the next step, and who ask what they need to do to handle the immediate problems in front of them." Financial pressures can become part of the caregiving equation as well. A study by researchers at San Francisco VA Medical Center found that caregivers of frail elderly relatives frequently miss work or quit their jobs altogether because of their responsibilities at home.

"Caregiving can be a huge financial strain upon families," says Mary Mittelman, DrPH, author of *Counseling the Alzheimer's Caregiver*. "But the emotional strain tends to be even greater."

## The Benefits of Caregiving

Although the stress and hardships of caregiving are undeniable, the experience isn't necessarily without positives. A study by Cohen, published in the February 2002 *International Journal of Geriatric Psychiatry*, evaluated close to 300 people (more than 30% of whom were men) who were caring for seniors. More than 70% of these caregivers said they were happy in the caregiving role, or had positive feelings about at least one aspect of it. Most commonly, they described enjoying the companionship, and the satisfaction of meeting an obligation and providing a better quality of life for the individual receiving care.

"Caregiving is a challenge and a difficult job for both men and women," says Cohen. "But the people who report finding positive aspects find it a little less challenging."

Leslie Gerber was the primary caregiver for his mother from the time of her diagnosis with Alzheimer's disease in 1995 until her death in January 2002 at age 85. "I was very close to my mother," says Gerber, who lives in New York City. "It was the right thing to do."

Nevertheless, Gerber admits to feeling plenty of frustration in the beginning, "but then I learned to just go with it." He handled many of his mother's immediate needs, managed her checkbook, and arranged for her doctors' appointments and trips to the beauty parlor until he finally hired live-in help to share some of the burdens. He also joined a support group sponsored by the Alzheimer's Association, which he found "very helpful in that it allowed me to meet others going through the same experiences." Beilin says that becoming active in the Well Spouse Foundation, and participating in one of its 50 active support groups, has helped him avoid burnout. "No matter how kind and considerate your friends and co-workers are, they can't fully understand what's happening to you and your family," he says. "I needed people to connect with who really understood the kind of emotional stress and pressure I was under."

## Getting Men Involved

Some studies have documented the ability of support groups to ease the emotional pain and anxiety and fight the social isolation associated with care giving. But even though these support groups for caregivers are available in most parts of the country, men lag behind women in their willingness to take the initiative to participate.

In an attempt to attract more men, the Alzheimer's Association sponsors support groups solely for male caregivers, which are becoming increasingly popular. O'Brien says that although the association offers services in more than 300 communities in the U.S., some men prefer participating more anonymously in online support groups through the organization's web site.

Men also tend to react differently to the depression that can accompany long-term care giving. They are less likely than women to admit that they feel depressed, and to talk with their doctor about it or to take antidepressant medication. Men, in fact, are more likely to deal with their depression by working long hours at the office or by abusing alcohol.

By contrast, women are often more receptive to counseling to manage their depression, says Khajit. "They cope with their emotions in a different way."

## Overlooking Self-Care

Male caregivers may neglect themselves in other areas -- eating an inadequate diet, ignoring their need for exercise, getting too little sleep, and postponing visits to the doctor for their own medical ills. But the consequences of these behaviors can be serious.

Recent research at Ohio State University found that the chronic stress associated with caring for a family member with dementia can weaken the disease-fighting immune system of elderly caregivers. At the University of Pittsburgh, investigators evaluated elderly individuals (48% of whom were men) who were caring for an ill spouse; the strain of caregiving increased

their risk of death, compared to counterparts who were not caregivers. As a result, many doctors and social workers tell caregivers that they can't care for someone else unless they're also caring for themselves.

"Caregivers often make themselves the last priority," says Khajit. "Some of them haven't had a day off in literally years. We talk to them about ways to arrange for a little time away so they can recharge their batteries and nourish themselves."

Mittelman, research associate professor of psychiatry at New York University School of Medicine, notes that if the caregiver isn't healthy, then the patient is going to suffer.

"Counselors often say, 'Take care of yourself because you're the only person who can take care of the patient,'" adds Mittelman.

Edited from MedicineNet.com.

*This article was forwarded by Linda Chen. Linda is a Board member of PPSG as well as the Palo Alto Support Group leader. Thanks so much, Linda!*

## SUPPORT GROUPS

**Berkeley:** 3<sup>rd</sup> Mon. North Berkeley Sr. Ctr. 1901 Hearst Ave. Call Mitzi at 510-527-9075, or Roddy at 510-231-1998

**Corte Madera (forming):** Diana Dunlap 415-927-4200

**Daly City:** 1<sup>st</sup> Tue. 3-4 pm, Doelger Ctr., 101 Lake Merced Blvd., Leonard Ke, 415-587-1285

**Fremont:** 4th Mon. 7:00 pm. Fremont Sr. Ctr. 40086 Paseo Padre Pkwy. Lettie 510-656-6393 or Bob 510-794-7988

**Caregiver:** Call Nancy at 510-574-2035

**Hollister:** 1st Tue. 1:30-3:30, 1st Presbyterian Ch., 2066 Cienega Rd. John 831-637-6755, or Shirley 831-637-3839.

**Los Altos-YPSG (Young Parkinson's):** 2<sup>nd</sup> Sat., 10-12 noon, United Methodist Church. Call Dean at 408-738-2505

**Magnolia/Peninsula:** 2nd Thur. 1:30 Magnolia of Millbrae, 201 Chadbourne Ave. Leon Rosenthal, 650-348-3480

**Marin County:** 4th Tue. 2-4, 40 Camino Alto, Mill Valley. Call Gloria Rashti 415-381-6680

**Merced:** 4<sup>th</sup> Thur. 10 am. Mission Gardens, 1450 E. 27<sup>th</sup> St., Merced. Call Amie at 209-384-3300

**Modesto:** 3<sup>rd</sup> Wed. 1:30-3:00, Centenary United Methodist Ch., 1911 Toyon Ave. JoAnn and David Ryan 209-529-5643

**Monterey:** 3rd Mon. 2:30-4:00, 200 Coe Ave., Seaside. Call Helen 831-657-4241 or Kathy 831-372-7510

**Mt. Diablo Parkinson's Network:** 2nd Mon. 11:00-2:30, 2100 Tice Valley Blvd., Walnut Creek. Margy Hansell 925-939-4210

**Mt. Diablo Early Onset:** 3rd Sat. 10-12, 2100 Tice Valley Blvd. Nancy 510-236-7065; Philip 510-527-3588

**Pleasanton Valley:** 2nd Sat. 10-12, Sr. Cnt. Call Cliff Terry at 925-935-1772.

**Walnut Creek Caregivers:** Last Wed. For time and place call Jewel 510-236-7065

**Oakland:** 1st Thur. 1:30-3:30, 180 Grand Ave., Ste. 300. Call Ardella at 510-835-2131 X103, or Robert at 510-526-2078

**Palo Alto:** 2nd Wed. 2-3:30, Avenidas Sr. Ctr., 450 Bryant St. Call Linda Chen 650-254-0906 or 650-289-5400 for directions

**Redwood City:** 3<sup>rd</sup> Fri. 1-2:30, Sequoia Hospital Health & Wellness Ctr. Call 650-367-5998

**Salinas:** 4th Wed. 2-3:30, Salinas Adult School, 20 Sherwood Pl. Elaine Viens, Delmar Research, 831-424-4359 X10

**San Francisco:** 3<sup>rd</sup> Thur. 5:30-7.00 pm, Holiday Inn Chinatown; 750 Kearny St.; free parking. Call Tom at 415-352-6514

**San Jose – Almaden/Blossom Valley:** 3<sup>rd</sup> Tue. 2:30-3:30 pm, The Atrium, 1009 Blossom River Way. Call Betty at 408-269-2167

**San Jose – Berryessa:** 1st Wed, 12:30-2, Berryessa Comm. Ctr., Bob & Jane Pomeroy 408-263-8485

**San Jose – Willow Glen:** 1st Fri. 10-noon, St. Francis Episcopal Ch., 1205 Pine Ave. Betty 408-269-2167

**San Jose Caregivers** 4th Wed. 1:30-3 pm, St. Francis Episcopal Ch. 1205 Pine Ave. Call Charmaine at 408-723-8116

**San Leandro:** 1<sup>st</sup> Thur. except summer, at 10 am, 13855 East 14<sup>th</sup> Street. Call Harry Santi at 510-351-3224

**San Mateo Caregivers:** 1st Wed. 2:30-4:30, Mills Health Ctr., 100 San Mateo Dr. 800-654-9966

**Santa Cruz:** 1st Wed. 12:30-2:30 St. Stephen's Lutheran Ch., 2500 Soquel Ave. David Donahoe 831-479-4485

**Saratoga:** 3rd Tue. 2-4, 19449 Via Real. Lois McPherson 408-867-1807

**Sonoma County:** 1st Sat. except Jan., July, Sept., 1 pm, 1st Cong. Ch., 2000 Humboldt St. Santa Rosa. Call Sue Croel at 707-544-5151 or Ron Trowse at 707-526-4373

**Sunnyvale:** 2nd Wed. 1-3, 535 Old San Francisco Rd. Call Linda 408-978-2859, or Henry and Phyllis 408-733-5648

**Tulare-Kings:** 1<sup>st</sup> Fri., at 10:30, Visalia United Methodist Ch., 5200 W. Caldwell Ave. Visalia. Call Donna Green at 559-307-4189

**Turlock (reforming)**

**Vallejo:** 3rd Mon. 2-4 (except 2nd Mon. in Jan. & Feb.); Kaiser Med. Ctr., 975 Sereno Drive. Evelyn Fox 707-644-3390

**YOPD:** 2nd Tue. 6:30-8pm, Lucile Packard Children's Hosp., 725 Welch Road, Palo Alto. Call Bill 831-662-3825

## EXERCISE CLASSES

**Berkeley:** Vista College, Joan Nielsen, 510-981-2800

**Berkeley:** Mon. 10:30-11:30 & 1-2:30, John Argue 510-985-2645

**Daly City:** Tue./Thur. 1-2, Doelger Sr. Ctr. Pat Armstrong 650-991-8012

**Gilroy:** Gavilan College, Dave Ellis, 408-848-4878

**Hayward:** Kaiser Permanente, Wed. 10-11:30, John Argue 510-985-2645

**Kensington:** Tue. 1:30-3:00, John Argue 510-985-2645

**Marin Cty:** Tue. 10-11:30; 12-1:30. Osher Marin JCC, San Rafael. 415-479-2000

**Monterey:** Monterey Peninsula College,

Mark Clements, 831-646-4231

**Orinda:** Tue. & Fri. 1:00-2:30, In Forma Gym. Dean Dallman 925-283-5019

**Palo Alto:** CAR, Aquatic Therapy, 650-494-1480

**Palo Alto:** Mon. & Fri., 9:15-10:15, Sr. Ctr. 450 Bryant St. 650-289-5400

**Redwood City:** Canada College, 4200 Farm Hill Blvd. Barbara McCarthy 650-306-3473

**Salinas:** Hartnell College, Melissa Stave, 831-755-6876

**Saratoga:** Mon. – Fri. 9-12; 1:30-3, W. Valley Comm. Coll. Joan 408-741-2420

**San Bruno:** Mon. & Wed. 1:10-2:30, Tue. & Thur. 12:35-1:50, Skyline Coll. Bess 650-738-4286

**San Francisco:** Fri. 11-12, SFSU, Marsha Melnick 415-338-1360.

**San Jose:** Mon. & Wed. 10:30-11:45, Hogue Ctr. Tue. & Thur. 10-11:45, Evergreen Ctr. Deanna, 408-369-6435

**San Jose:** Easter Seals Comm Ctr. Aquatic Exercise programs, 408-295-0228

**San Jose:** Evergreen Valley College, Rich Wagner, 408-274-7900 X 6447

**San Mateo:** College of San Mateo, 1700 W. Hillsdale Blvd., John Hogan, 650-574-6469

**Sunnyvale:** Tue. & Thur. 9-10, Sr. Ctr. 550 Remington Dr. Ruth Hanes 408-864-8873

## 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**

## 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 Way), Berkeley, and the meeting time is **10:00 AM-12:00 noon.**

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



## 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 September 26 meeting consisted of a rap session during which we discussed future plans for the group, as well as the usual sharing of information.

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

## 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

**Thursday, October 13** - \*Dr. Michael Aminoff, professor of neurology at UCSF, will discuss gene therapy.

**Thursday, November 10** - \*Dr. Grace Liang, recent addition to the staff of the Parkinson's Institute, will bring a fresh perspective to treatments.

No meeting in December!

\*tentative

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

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**.

## Merced, New Group

We normally meet the **4th Thursday** of each month at **10AM**. Our Sept. 22 meeting featured Janie Shofner, MSW, who presented information on anxiety and depression.

We meet at Mission Gardens, 1450 E. 27th Street, Merced, CA 95340. For more information people may contact **Amie Marchim** at **209.384.3300**. Due to holidays the rest of the year our schedule is as follows: Oct. 27, Nov 17 no meeting in December.

## **Modesto, new group**

Modesto Parkinson's Support Group meets on the **3<sup>rd</sup> Wednesdays**, 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**

**Basic meeting:** Meets on **2<sup>nd</sup> Mondays** from **11 AM-2:30 PM** at Grace Presbyterian Church, 2100 Tice Valley Blvd., Walnut Creek. The meeting includes a speaker, light lunch, exercise, and discussion groups. Contact **Margy Hansell** at **925.939.4210**.

**Early Onset Support Group:** Meets on **3<sup>rd</sup> Saturdays** from **10 AM-noon** at Grace Presbyterian Church, 2100 Tice Valley Blvd., Walnut Creek. Call **Nancy Wall** at **510.236.7065**, or **Philip Wheeler** at **510.527.3588**.

**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**

**December 1**, Marilyn Basham, Outreach Coordinator, The Parkinson's Institute.

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**

**October 12 speaker: Julie Groves**, an occupational therapist.

**November 9 speaker: Dr. Huang** from TPI.

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 **650.289.5400**

## **Redwood City**

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

**Positive People Against Parkinson's, the Redwood City Parkinson's Support Group**, will meet for the next few months in **Conference Room G** at **Sequoia Hospital, 170 Alameda De Las Pulgas** (at Whipple), Redwood City.

Valet parking is available at the hospital's entrance. No tipping please.

Our featured speaker for the September 16 meeting was the informative Clinical Psychologist Nurse Ann Wilkinson. Ann came to our group about a year ago and was back again by popular demand! Ann discussed the importance of being positive, which is in our name.

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

## 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 **Elaine Viens** at Delmar Research, **831.424.4359 x10**.

## San Francisco

The group meets on the **3<sup>rd</sup> Thursday** of the month, at Holiday Inn Chinatown, corner of Washington & Kearny. (Hotel parking is free for this meeting!) For meeting time, call **Tom O'Brien** at **415.352.6514**.

## San Jose – Almaden/ Blossom Valley (New)

At our meeting Tuesday, August 16, there were 7 of us, fewer than last time. One regular couple and one new gentleman with Parkinson's, 3 former caregivers and one man possibly with Essential Tremor. We had a good conversation about some problems, and good advice from one of the experienced caregivers.

Our meeting on September 20 had 10 people in attendance - 4 patients and caregivers. Everyone had questions and comments which were pertinent to the group, and ideas and solutions were passed around. We will be losing one couple as they move to Gilroy but there will be others.

The group meets on the **3<sup>rd</sup> Tuesdays** of the month, from **2:30 to 3:30 PM**, at The Atrium Retirement Community Center, 1009 Blossom River Way, San Jose. For meeting information, please contact **Betty Havens** at **408.269.2167**.

## 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

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 September meeting speaker was Carol Evans, Kaiser Hayward Parkinson's Nurse.

The speaker for the October meeting was Randy Hoffman, Speech and Language Pathologist at Parkinson's Institute.

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 **Mills Health Center**, at **800.654.9966**.

## 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 **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.

For a portion of each meeting the participants are divided into caregivers' and Parkinsonian sessions. They are divided so that all have an opportunity to speak freely about their cares and concerns.

Call **Ron Trowse** 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 Trowse at 707.526.4373.

## Sunnyvale

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, please call **Linda Filice** at **408.978.2859** or **Phyllis and Henry Ng** at **408.733.5648**.

## Tulare-Kings

At the August 5 meeting, we had a program titled "Motivating Moves for People with Parkinson's" along with Janet Hamburg's Seated Exercise Program.

For the September 2 meeting, we had Darryl Prince as our speaker. Darryl is a social worker for the Tulare County and the title for the talk was "Stress and Depression."

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 **Donna Green (new leader)**, at **559.307.4189**, or the church office at **559.627.1660**.

## Vallejo

We are 10 years old! The Vallejo Parkinson's Support Group celebrated our 10 years of service in April with a luncheon put on by four of our members. The Vice Mayor of Vallejo presented us with a Proclamation from the city on successfully having served the community for 10 years. The Chief of Staff from Kaiser Vallejo took time to join us and thank me for having the Parkinson's Support Group available to Parkinson people and anyone interested in knowing more about Parkinson. I, Evelyn Fox, in turn thanked him for letting us use the Conference Rooms for our meetings. Mr. Armstrong from Kaiser's Health Education put together goodie bags for us. Over the years we have had many people that left a rewarding impression with us while they were able to attend the meetings.

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**.

## Scientists Discover How Fish Oil Protects the Brain

By Karen Pallarito  
*HealthDay Reporter*

FRIDAY, Sept. 9 (HealthDay News) -- Louisiana State University scientists say they have discovered how the fatty acids found in fish oil help protect the human brain from the type of cognitive decline associated with Alzheimer's disease.

Their study shows that docosahexaenoic acid (DHA), an omega-3 fatty acid found in coldwater fish such as mackerel, sardines and salmon, reduces levels of a protein known to cause damaging plaques in the brains of Alzheimer's patients.

What's more, the researchers discovered that a derivative of DHA, which they dubbed "neuroprotectin D1" (NPD1), is made in the human brain. That natural substance plays a key role, too, in protecting the brain from cell death, the study showed.

"Now what does this tell us from the point of view of the disease? I believe that, obviously, diet is a major issue here," said Dr. Nicolas G. Bazan, director of the Neuroscience Center of Excellence at the Louisiana State University Health Sciences Center in New Orleans.

"DHA is an essential building block for the structure of brain cells," he noted. "And now we are finding that this building block also makes a 'golden brick' (NPD1) that helps the life of the neurons to continue."

Greg M. Cole, associate director of the Alzheimer's Disease Research Center at the University of California, Los Angeles David Geffen School of Medicine, said the study

"provides strong evidence" that NPD1 offers "several important protective contributions."

The study was released online Sept. 8, in advance of its Oct. 1 publication in the *Journal of Clinical Investigation*.

Indeed, while previous studies have suggested that DHA reduces the risk of Alzheimer's-related cognitive deficits, scientists haven't explored how the fatty acid may work its protective magic.

Some 4.5 million Americans have Alzheimer's disease, according to the Alzheimer's Association. If no cure is found, as many as 16 million could have the disease by 2050, as the population ages.

Bazan and colleagues at LSU and Brigham & Women's Hospital in Boston conducted a series of experiments. Some of the testing involved postmortem human brain samples harvested from six patients who had Alzheimer's disease and an equal number of age-matched "control" samples from people who did not have the disease.

The researchers also used technology called tandem mass spectrometry to analyze changes within brain cells.

Studies show DHA is highly concentrated in the brain and retina of the eye. In earlier research, Bazan's team discovered that NPD1 is produced in cells that are critical for vision. They wondered whether the brain might do the same.

"And the human brain, sure enough, makes neuroprotectin D1," Bazan found.

Cole, the UCLA researcher, noted: "This study also shows that both DHA and its NPD1 product are effective in treating human brain cells and reducing the inflammation and toxicity from a toxin

called beta amyloid that is widely believed to cause Alzheimer's."

The researchers also examined specific areas of the brains of people with Alzheimer's, including an area critical to memory formation and cognition. "And that area shows huge -- I mean 20-, 25-fold -- decreases in neuroprotectin D1, as compared with other areas in the same human brain," Bazan said.

Furthermore, in cell studies designed to mimic the effects of aging, the team found that adding DHA reduced the secretion of toxic beta amyloid proteins and, at the same time, spurred production of NPD1.

"We are concluding that neuroprotectin D1 induces a gene expression program that is neuroprotective, meaning that it promotes survival of brain cells," Bazan said. And that discovery, he added, could one day lead to the development of a new treatment to slow the progression of Alzheimer's disease.

For now, though, people should pursue a nutritional approach to warding off Alzheimer's and diminishing the effects of the disease.

Since DHA sources are safe, cheap, available and clinically proven to fight heart disease, the nation's number one killer, Cole said he would advise families of Alzheimer's patients to make sure their loved ones get the minimum recommended DHA from their diet or supplements. Experts recommend 200 to 300 milligrams per day, a far greater amount than the 60 to 80 milligrams daily that Americans typically get in their diet, he noted.

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

## PPSG Board Meetings

We welcome anyone to drop by our board meetings and share ideas with us! We meet on the **3rd Wednesday** of the month between **1:00 and 3:00 PM** at the Parkinson's Institute in Sunnyvale. The next 2 board meetings are October 19 and November 16. To confirm meeting dates and time, please call us at 408.734.1593.

### **Brain inflammation 'initiates' Parkinson's**

**Last Update:** Sunday, September 25, 2005. 4:00pm (AEST)

Researchers in Sydney say they have made a significant discovery about Parkinson's disease.

The Prince of Wales Medical Research Institute says it has found that the immune system plays a role in the development of the disease by attacking parts of the brain.

The institute says it was previously thought that inflammation of the brain associated with Parkinson's was a consequence of the disease.

But researchers say the inflammation is actually an initiator of Parkinson's.

They say the discovery means that treatment with anti-inflammatory drugs may arrest brain degeneration in sufferers.

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- ?? Updated events in the area
- ?? Support group locations, times and contacts
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- ?? Interesting links to Parkinson's patient and caregiver sites
- ?? News on Parkinson's developments

## In Honor

PPSG recently received a gift donation in honor of the following individual:  
Charmaine Eng.

## In Memory

PPSG recently received gift donations in memory of the following individuals:  
Mok-Yuet Tsui Chao, Jerry Havens, Taylor Howard, Luther Linkhart, Mary Nederostek, Anthony Ponza, Francis Sedlacek, and Elese Sindici.

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*Fall Quarterly 2005*

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