

Parkinson's Patients Support Groups, Inc.

Nov/Dec 2005

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Act Now to Stop the Therapy Cap!

Unless Congress takes action this fall, Medicare enrollees will once again face having their physical therapy benefits arbitrarily capped beginning January 1, 2006, regardless of their medical condition or rehabilitation needs.

Legislation to repeal the Medicare therapy cap has been introduced – the "Medicare Access to Rehabilitation Services Act" (H.R. 916/S. 438) has strong bipartisan support in both chambers of Congress. In the current budget environment it may prove impossible to repeal the cap entirely – but it is crucial that Congress pass legislation in the coming weeks to protect Medicare beneficiaries' access to essential rehabilitation care.

Uncertain Future Awaits Therapy Cap Repeal Bills in Congress

Congressmen Phil English (R-PA), Ben Cardin (D-MD), Roy Blunt (R-MO), and Frank Pallone (D-NJ) and Senators John Ensign (R-NV) and Blanche Lincoln (D-AR) introduced legislation February 17, 2005, that would repeal the cap on therapy services for Medicare beneficiaries once and for all (HR 916/S, 438). If Congress does not take action by January 1, 2006, the cap will be imposed on PT, OT, and Speech services. You need to take action **NOW** to ensure the cap does not go back into place. The House budget committee also included report language in the House version of the FY 2006 Budget Resolution

recognizing the therapy cap issue and its impact on beneficiaries' access to rehabilitation services provided by physical therapists. The language reads as follows:

Physical Therapy Caps

"The committee recognizes the importance of patient access to high-quality rehabilitation services for Medicare beneficiaries and supports continued monitoring of the implementation of the Medicare Modernization Act of 2003 and beneficiary access to rehabilitation services for Medicare beneficiaries."

This language is an important first step to ensure that Medicare legislation addressed by the committees of jurisdiction in 2005 will consider the therapy cap issue.

Background on Therapy Cap The Medicare cap on outpatient rehabilitation therapy services was originally instituted under the Balanced Budget Act of 1997 as a combined cap on speech-language pathology (SLP) and physical therapy (PT) services, as well as a separate cap on occupational therapy (OT) services to Medicare beneficiaries.

The original \$1500 cap on Part B Medicare therapy services was intended as a cost control mechanism, but has not proved effective in saving Medicare money. Instead, it has punished the sickest of Medicare patients and denied them needed care. Congress has already recognized

that the \$1500 cap is detrimental to Medicare patients by temporarily suspending the cap. This moratorium has been extended several times, but the caps will go back into place unless Congress acts by December 31, 2005. S. 438 and H.R. 916 would deal with the problem, by repealing this arbitrary and punitive limit outright.

Model Letter for Patients on Lifting the Therapy Cap

Date _____

The Honorable _____

U.S. Senate/U.S. House of Representatives

Washington, DC 20510/20515

Dear Senator/Representative

_____:

As a concerned constituent and a patient, I am writing to you about a provision that originated in the Balanced Budget Act (BBA) of 1997 that harmed senior citizens in 1999 and could do so again effective January 1, 2006. This provision would impose an approximate annual limit of about \$1,700 on my outpatient therapy services next year. This limitation, or cap, affects therapy services provided in all Part B practice settings except for those furnished in a hospital outpatient department. Congress has recognized the potential consequences of the therapy cap and on three separate occasions imposed a moratorium to prevent its implementation. Therefore, I urge you to take action to remove the cap on therapy services and prevent harm to Medicare patients like me.

Congress is well aware of the inherent problems with the therapy cap.

· The arbitrary therapy cap (approximately \$1,700 in 2006) will have a disproportionate impact on those Medicare beneficiaries who need therapy care the most – the oldest and the sickest – denying access to essential care for the most vulnerable Medicare population.

· Beneficiaries who require services above the \$1,700 level will be forced to seek that care in an outpatient hospital department – if one is available to them in their area – or face paying 100 percent of the cost of additional treatment out of their own pockets.

· This arbitrary cap will limit access to necessary therapy if a patient has more than one episode of care for therapy in a year – not uncommon for Medicare beneficiaries. For example, if a Medicare patient has a knee replacement and receives \$1,700 in therapy – and then suffers a stroke or some other condition that requires therapy care later in the same calendar year, Medicare will not cover those services if the \$1,700 limit has already been reached.

Senators John Ensign (R-NV) and Blanche Lincoln (D-AR) have joined with Representatives Phil English (R-PA), Ben Cardin (D-MD), Roy Blunt (R-MO), and Frank Pallone (D-NJ) in introducing the “Medicare Access to Rehabilitation Services Act” (S. 438/H.R. 916). This legislation would repeal the arbitrary cap on therapy benefits once and for all. I strongly urge you to cosponsor this important legislation and actively work for its adoption as soon as possible this year. I don’t want to suffer irreparable medical and economic harm because there is a cap on my therapy services.

Thank you for your consideration. I look forward to hearing of your support of the Medicare Access to Rehabilitation Services Act (S. 438/HR 916) and your action to repeal the therapy cap.

Sincerely,

(Your Name)

Marilyn Basham, at the Parkinson’s Institute, forwarded this important information. Thanks, Marilyn.

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

A Special Thank-You

On September 28, around 20 caregivers were invited by **Le Sotir** to her lovely home for a fabulous luncheon. Attendees enjoyed delicious fruit drinks, seafood pasta, Greek salad, chicken salad, and also tasty chopped apple cake baked by **Charmaine Eng**. The weather was beautiful and all appreciated the special occasion provided by our gracious host. Thanks so much, Le!

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 **3rd 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 **Mitzi Cahn** at **510.527.9075** or **Roddy** at **510.231.1998**.

Daly City

The Daly City Support Group meets on the **1st 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

Our October speakers were Kelly Hayes, Director of Development, and Marilyn Basham, Physical Therapist, both from Parkinson's Institute. Their presentations were very interesting. Thank you, Kelly and Marilyn.

We regret to announce that one of our most faithful members, Manuel Terra, passed away recently. We wish to express our condolences to his family, and we gave a donation to the Parkinson's Institute in Sunnyvale in his memory.

The Fremont Support Group meetings are held on the **4th 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, 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!

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 **2nd 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 **4th 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 **3rd 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 **3rd 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 **2nd 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 **3rd 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 **2nd 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 **1st 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 **2nd 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**.

Redwood City

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

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 October 21 meeting featured Joe Marchi, retired Cañada College professor. March is one of the nation's leading authorities on the American musical. Joe was back by popular demand.

No meetings in November and December.

PPAP-Positive People Against Parkinson's-meets on the **3rd 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 the meetings.

Salinas

The Salinas Support Group meets every **4th 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 **3rd 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

The group meets on the **3rd Tuesday** 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 **1st 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 **1st 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 **4th 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 **1st Thursday** of the month, **except July and August**, at **10 AM**, at the Education Center of San Leandro Hospital, 13855 East 14th 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 **1st 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 **1st 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 **3rd 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 **1st 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

Dr. Dawn McGuire and Mary Tilson from Avigen, Inc. were our October guests. Dr. McGuire spoke to us about the gene therapy trials that are going on at UCSF. Dr. McGuire gave an excellent presentation on gene therapy methods and answered many questions from our members. We had a very good turnout. We would like to thank Dr. McGuire and Mary for making a special trip.

Our **November 9** meeting will be a special **Thanksgiving feast**, provided by **Le Sotir**. Le has done such wonderful luncheons for us the past two years. Thanks so much, Le! A special thank-you to **Maxine Voight**, our hostess at the meetings, also **Janet Banks & Hazel Kuhl** who make calls to members with upcoming activities.

The Sunnyvale Support Group meets on the **2nd 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

At our September meeting, the group voted to send \$100 to the Red Cross to help with Katrina Relief.

Our October 7 speaker was Dr. Carmina Karmay Kwong. The topic was "Acupuncture, Herbal Medicine and Parkinson's." Dr. Kwong has a degree in Oriental Medicine.

The November 4 speaker is Attorney Sarah Shena from Kings/Tulare Area Agency on Aging. The topic is "Legal Issues, including Durable Powers of Attorney for Health Care and Living Trusts."

The December 2 meeting features a Christmas Party. Come try our famous tortellini soup!

The Tulare-Kings group meets on the **1st 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

The group meets on the **3rd Monday** of the month, **except January and February**, when they meet on the **2nd 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 **2nd Tuesday** of every month, from **6:30 to 8 PM**. For information, please call **Bill Lev** at **831.662.3825**.

Fall Caregiver Retreat Report

By Darrell McCleod

Do you ever feel as if you are running out of gas? No, not your car, you! Do you ever feel as if you are living with someone you don't like very much? No, not the one you care for, but you! Sometimes I find that I have gotten irritable, angry and just plain unpleasant with loved ones and people that I am caring for. At times like that it is very appropriate to take a weekend of "me" time. That is exactly what 25 caregivers did during October 7-9, 2005, through Family Caregiver Alliance at their Fall Caregivers Retreat. We convened at 3:00 pm on Friday at the approximately 100-year-old Ralston L. White Retreat located in the foothills of Mill Valley. It was a beautiful, albeit "white knuckles" ride up what turned out to be a one-lane road in the redwoods overlooking the San Francisco Bay and the Golden Gate Bridge. We were treated to "home cooked" meals,

entertained Friday night by the San Francisco Improvisational Theater Alliance, followed by a night of movies with popcorn. Saturday and Sunday we had gentle stretching, yoga and breathing exercises lead by Mary Beth Ryan, R.N., group discussions expertly led by Donna Schempp, LCSW, and John Jeffery, MD, massages, hikes, ping-pong, collage making, a casino night (Black Jack or Texas Hold-Em Poker) with prizes for the two top winners.

Does a week-end retreat change the life of a caregiver? Nothing can change the fact that caregiving is hard and caregivers get tired, irritable, even unpleasant and angry at themselves and the ones that they are caring for. It is possible to understand our situation a little better, to take care of ourselves a little more, to set priorities and boundaries, and to understand ourselves a little better. Sometimes that only thing that you can ultimately change is your attitude and your state of tiredness! I know that this weekend worked for me, and I think that it worked for the majority of the 25 caregivers that attended the retreat. If you have not made contact with the Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, California 94104, (800) 445-8106, maybe it is time that you should. It is just one more resource for you, and ultimately resources for you are resources for the loved ones that you are caring for.

Marge Shively, our long-time PPSG Board Member, recently left to focus on other responsibilities. Marge has always been very generous with her time and talents and had made major contributions to PPSG & the PD communities. **Thanks so much, Marge!**

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. To confirm meeting dates and time, please call us at 408.734.1593.

Adopting the Right Attitude

By Leon Rosenthal

Magnolia-Peninsula Support Group Leader

Until my late sixties I had not taken more than a couple of dozen aspirin in my entire life. Now, I have red pills, blue pills, big pills, little pills. Here's how it all came about.

In the mid-nineties my wife and I were visiting our daughter and her family in Los Angeles. One day I was asked to pick up my granddaughter from her dance class. While I was waiting outside, she ran up behind me, wrapped her arms around my legs forcefully, and gave me a big hug. I fell down, and she fell also. I didn't think too much of it, but shortly after, I took another tumble over a concrete car stop in a parking lot.

I also began to develop some pronounced aches in my shoulders and back, and I noticed a slight tremor in my right hand, particularly when I was cold or under stress. So I went to see our family doctor. He promptly referred me to a neurologist, who tapped me on the knee, had me count backwards from a hundred, and questioned me as to what day, month, and year it was. The neurologist wound up his examination by shrugging his shoulders and telling me the tests were inconclusive. He suggested I return in six months.

Being the impatient sort, I didn't want to wait. I knew there was something wrong with me, and I wanted to know what it was. I discovered that there was a clinic, The Parkinson's Institute, that specialized in Parkinson's and other movement disorders. Despite the fact that my health insurance company refused to pay for a comprehensive examination, I made an appointment, received a thorough examination, and was told that I definitely had Parkinson's disease.

At that time, I didn't know much about Parkinson's, but the neurologist that examined me informed me that it's a progressive disease, with no known cure. He told me that it probably wouldn't kill me, but I likely would wind up in a wheelchair, unable to fend for myself. I was devastated. I went home, poured myself a stiff drink, sat down, and felt sorry for myself. Two questions kept flashing through my mind: How would my wife react? And, how would this news impact our retirement nest egg?

I concluded that I had three choices:

1) I could commit suicide and save my family and myself grief. I ruled this out because of my belief in the sacredness of life, and also, perhaps, due to cowardice.

2) I could wring my hands and resign myself to my fate or,

3) I could, perhaps with others, try to do something about it.

I chose the third option, and I haven't ever regretted it. I feel at times that I'm on a holy mission, and, at other times, as if I'm engaged in detective work. My first objective was to learn as much as I could about the disease. I asked lots of questions, subscribed to a myriad of publications, and began compiling a list of outstanding research institutions and individuals engaged in cutting-edge work on diseases of the brain.

I discovered that there is a protein called dopamine, housed in a part of the brain known as the substantia nigra. When a substantial amount of dopamine, roughly 80%, leaks out of the substantia nigra, one begins to lose control over one's motor functions, and awkward, contorted, and uncontrollable body movements, known as dyskinesia, set in. Because it is a protein, dopamine is too large to penetrate the blood-brain barrier, and so reliance has to be on drugs that mimic dopamine and can get through the barrier.

Concern about breaking the news to my wife turned out to be unnecessary. Her ability to handle my growing physical shortcomings has only increased my love and admiration for her. If anything, the experience has brought us closer. And, as for financial worries, I've been able to use the marvelous prescription service offered by our local V.A. hospital at a modest cost.

Among the medications I take are Agonists, MAO Inhibitors, and a Carbidopa-Levodopa combination. They are palliatives that do not offer long-range relief, but, in most cases, they give temporary respite from many annoying and painful symptoms of Parkinson's. One of my major frustrations is that, in addition to there being no known cure, no one seems to know for sure what causes Parkinson's. I happen to feel that it's environmentally caused.

For ten years, during the 1960s, we lived in the Los Angeles area, in a new development of homes built

over abandoned oil wells. Through a friend who lived in the area until recently, we've been able to identify five people on one block who have contracted Parkinson's. Since this seems more than a coincidence to me, I passed the information on to The Parkinson's Institute. They have promised to investigate further.

With my wonderful wife, who has supported and encouraged me, I visited numerous institutions, volunteered to be a guinea pig for new medications, and immersed myself in all aspects of what has proven to be an absorbing and fascinating journey.

Our travels took us as far as Israel, where we were immensely impressed with the brilliant, dedicated people working toward cures for some of the most intractable ailments. It was a special thrill for me to meet the discoverer of one of the medications (Selegiline) I now take.

Having attended Johns Hopkins University in Baltimore, I've always had the greatest respect for their scientific prowess. Now they have come to the fore in a number of important ways. One of Hopkins's leading scientists, Elias Zerhouni, was appointed by President Bush to head the National Institutes of Health. It has been my good fortune to meet several of the scientific researchers at Hopkins, including such luminaries as Dr. John Gearhart, who co-discovered the embryonic stem cell. Hopkins has received two record-setting donations, one for one hundred fifty million dollars to establish a comprehensive cancer center and another gift for fifty eight million dollars to establish an "Institute for Stem Cell Research."

I've become acquainted with neurologists at the University of San Francisco Medical Center, and others at the V.A. hospitals in both San Francisco and Palo Alto, California. I've also been communicating with researchers at Columbia, The University of Southern California, and The Center for Movement Disorders at Stanford.

I was diagnosed in 1994; in 1995 I volunteered for a test of a new drug being conducted at the National Institutes of Health. Unfortunately, the drug caused liver damage, and so the test was aborted. But, I met some wonderfully caring and dedicated people at The Institutes, and I've continued to stay in touch with them.

In 2001 Amgen, one of the world's leading biotech firms, launched a double-blind, phase two, six-month trial of a medication originally developed by Dr. Solomon Snyder and colleagues at Hopkins. In blind studies some of the participants receive a placebo and some get the actual drug. However, in a double-blind study, neither those administering the test nor the patients are aware of what is being dispensed to whom.

Phase two means the test is conducted with human subjects afflicted with the disease. Before that, testing is usually done on various animals. Again I volunteered and was accepted, and now that the trial is over, I'm anxiously waiting to find out what will happen. I did discover that I was given the actual drug, as opposed to a placebo. I felt it was quite beneficial to me in a number of ways. For example, I had been plagued by constipation and the inability to sleep beyond three A.M. Both of these problems disappeared completely while I was taking the test medication.

Phase three is generally a much longer trial, perhaps over two years, after which FDA approval is sought, providing that the drug has been effective.

Another aspect of my involvement with the world of Parkinson's concerns support groups. After learning that I had Parkinson's, I found out that there was a support group meeting regularly at a church in our neighborhood. I attended one meeting and that was enough for me! I came away far more depressed than when I had gone in. There was nothing of a positive nature at the meeting.

Shortly after that, I discovered that two friends also had Parkinson's and they, too, were at loose ends. So, we started our own little group, meeting monthly.

We discovered that there were a number of others in the area, hungry for information and camaraderie. Before we knew it, our membership had grown to 25, a number hard to accommodate in our home. Fortunately, several years ago we had been contacted by the management of a senior residence facility that had ten residents with Parkinson's and no formal program for them. We were invited to use their conference room, if we included their residents in our meetings.

We now have 84 members with Parkinson's on our roster and a very comfortable meeting facility. Our meetings are upbeat and full of hope. We have had a variety of speakers on various problems associated with Parkinson's. Our mission is one of exchanging information in a positive manner. We try to stay in touch with people doing cutting-edge research.

In this world of indifference, it has been immensely gratifying to find so many scientists who have opened their doors and their hearts to a total stranger. I have been truly blessed.

My message is one of hope and confidence in the future. I am convinced that a cure for Parkinson's is just around the corner. However, we need to help hasten the process by supporting the push for adequate government funding, by volunteering for trials of new medications, and by staying informed. Carpe diem!

Addendum, September 12, 2005

Yesterday the TV program "Sixty Minutes" had a segment devoted to trying to receive a continuous supply of experimental medications when that medication seems to be beneficial to those in the study. The episode concerned GDNF, an Amgen-sponsored study, in which a number of Northern Californians with Parkinson's were enrolled. I was in an earlier trial of a drug developed by Hopkins scientists referred to above, also sponsored by Amgen. I suspect that Amgen's motivation in discontinuing experimental medications is based on the profit potential that it anticipates.

Free air boots, used to protect the feet in bed or sitting (like new). Also egg carton chair pads and other foam pillows and bolsters a variety of knee and back supports. Call **650.948.3192** for descriptions.

Shively

Marge Shively was raised in Alameda in the same house where her mother still lives. She received her

Bachelor's Degree from Cal and Master's Degree from Stanford making rooting for Big Game interesting! She taught physical education at San Carlos and Ravenswood High Schools for nine (9) years before stopping to raise her daughter. As her daughter grew, Marge started teaching perceptual motor training in preschool and adapted physical education in the Los Altos Elementary School District. Later, she added exercise classes in the Los Altos Mountain View Adult Education District, focusing on older adults, many in the convalescent homes. Before retiring, she taught adapted physical education for 18 years in the Foothill De Anza Community College District. Most of her classes were at the local senior centers, especially Avenidas where she taught the same classes for 15 years. Her specialties were gentle and chair exercise, back fitness, water exercise and classes for people with arthritis.

One of her assignments for Foothill was an exercise class that had mostly folks with Parkinson's disease (PD). She became interested in PD, joined the Board of Directors for PPSG (then Peninsula Parkinson's Support Groups Inc., now Parkinson's Patients Support Groups Inc.). She taught many classes for people with Parkinson's, gave private lessons, and led a support group. With mixed emotions, after 11 years, she retired, from the PPSG Board in September 2005.

Marge met her husband, Jim, at Cal. They have lived in Redwood City, Palo Alto, and for the past 38 years, Los Altos Hills. Jim was the treasurer on the PPSG Board for several years. They have one daughter, Linda, who lives in Fremont with her husband Cledwyn, and daughter Jessica. Jessica was born in January 2002 and diagnosed with Spinal Muscular Atrophy (SMA) that April. SMA is the leading genetic cause of death of children under two. And now Marge has a new career of raising

awareness and funding for research for SMA. Research is quite promising and international researchers claim that

of all the neuromuscular diseases, SMA is closest to a cure. See www.CureSMA.org for more information about this devastating disease.

For fun, Marge enjoys painting porcelain china. She and Jim belong to a Corvette club and go on drives with them about once a month. They also enjoy the local theaters and museums.

Do You Have Difficulty Hearing?

Visit the PPSG Website

www.ppsg.org

Marge,
by Marge

By Evelyn Merritt

Do you ever feel as if people are mumbling? Is it getting harder to understand what people are saying, especially when there is noise in the background? These are signs of hearing loss, which, like many things, can happen as we get older. Unfortunately, hearing loss sometimes leads to isolation, as people spend time alone when they feel they miss out on conversations. Here is an explanation of how hearing loss works and some tips to help hear better in difficult situations.

A typical hearing loss involves losing hearing in the high frequencies. That is where many sounds of speech are that make speech understandable. Therefore, although we may hear people talking, we may not necessarily understand what they are saying. This is why it may appear that people are mumbling. This problem is exacerbated with background noise which is a low frequency sound. We can hear the noise very loudly, but the speech very softly.

Here are a few things to do in difficult situations to improve your ability to hear. If you know you are going into a noisy situation, such as a cafeteria, and you are going with a partner, make sure you sit next to that partner and face her when you speak to her. Seeing their face and lips and hearing up close will greatly enhance your ability to understand the conversation.

Also, when talking to someone, and missing a key element of his sentence, instead of just saying "what," try repeating back to him the part that you did hear and only asking for the part you missed. For example, somebody says, "John is coming on the train today at 6:00." Instead of just saying, "what," say, "I heard John is coming on the train, what time did you say?" This will make the conversation flow much easier and reduce frustration.

If you are having specific problems with the telephone or television, there is special equipment that can help you with that too. If you go to a doctor or audiologist, they will give you a note that you can send to the phone company, which will give you a special amplified phone that will make it easier to hear people on the line. For television, there are special FM systems that can be purchased in stores. You place the FM transmitter on the TV, and place

headphones on your head, and this makes listening to TV much easier.

Evelyn Merritt is an audiologist who graduated from San Jose State and now teaches there on a part time basis to help students get their audiology hours on their way to Speech Pathology degrees. Thanks, Evelyn.

Do You Need Help Caring for Your Aging Parent or Family Member?

You may have many concerns, including questions about transportation, money management and living options for your aging parent or family member. Perhaps you are not yet in need of answers, but would like to plan now for needs that may arise in the future. Planning now will help you and your family to avoid having to make decisions in a crisis.

Family Caregiver Assistance can help save you time, money and energy.

Family Caregiver Assistance is a unique professional service that will help you:

- ✂✂ Develop a care plan
- ✂✂ Evaluate financial circumstances
- ✂✂ Identify your needs and concerns
- ✂✂ Locate local and nationwide caregiver resources
- ✂✂ Receive continued confidential support
- ✂✂ Receive selected printed materials specific to your needs
- ✂✂ Set priorities and find practical solutions

Have you asked yourself these questions?

- ✂✂ How do I manage the demands of my family, my job and caring for my parent?
- ✂✂ How can I help my family member remain independent?
- ✂✂ Do I need to move my family member close to me?
- ✂✂ What is the difference between assisted living, residential care and skilled care? How do I find these resources?

The Health Resource Center & medical Library at El Camino Hospital is located at 2500 Grant Road, Mountain View, CA and the phone number is **650.988.7622**. www.elcaminohospital.org

The elderly are especially vulnerable to **pneumonia**. It is important the doctor is called when there is a fever lasting longer than a few days, a wet cough, pain when taking deep breaths, and shortness of breath. This may be pneumonia, which can be fatal to the elderly.

Adapted from Avenidas, January 2003.

Wintertime Safety and Comfort

During the winter months, there are simple things we can do to increase safety, reduce heating bills, and make the cold weather months easier to handle.

Winter Safety Tips

- ✍ Install an extra smoke detector near heating sources like space heaters and fireplaces when you start to use them in the winter months. Change smoke alarm batteries twice a year.
- ✍ Keep space heaters at least three feet away from flammable objects such as curtains and upholstered chairs. Also, don't use extension cords with space heaters or run electrical cords under carpets.
- ✍ Keep a fire extinguisher in the house and know how to use it.
- ✍ Use liquid-fueled heaters only in well-ventilated areas to prevent carbon monoxide poisoning.
- ✍ Have the furnace serviced every year to keep filters clean.

Keeping the House Warm

- ✍ Place a thermometer indoors where the senior can check easily to make sure the house is warm enough (at least 65 degrees F °).
- ✍ Make sure that the fireplace flue is closed when not in use to prevent cold air from blowing in. Always re-open it before lighting a fire.
- ✍ Weatherproof the house with storm windows, weather stripping in door crack and insulation. A rolled blanket or towel next to a drafty opening is a quick-fix.

Edited from Avenidas, January 2003 issue; forwarded by Marge Shively.

Charles (Charlie) C. Hanna, Ed. D.

August 29, 1930 – September 17, 2005

Dr. Hanna passed away in Sunnyvale, CA, following a long illness resulting from Parkinson's disease. A native of Minnesota, Dr. Hanna served as Associate Vice President for Academic Affairs, Dean of the Graduate School, and Professor of Educational Administration at California State University, Stanislaus. An ardent golfer, Dr. Hanna was past Board President of the Turlock Golf and Country Club. He was a volunteer Board Member of Modesto's Family Service Agency, as well as an active member of the Turlock VFW. His professional career and his personal life were characterized by humor, intelligence, and integrity. He is survived by his wife Barbara, his son Chuck Hanna and family, and his daughter Linda Chen and family.

Remembrances may be made to Faith Home Teen Challenge, P.O. Box 611 Turlock, Ca 95381.

We would like to express our deepest sympathy to Linda Chen and her family. Linda is a PPSG board member and the Palo Alto Support Group leader.

2006 PPSG Board Members and Officers

PPSG has recently nominated the following board of Directors and Officers for 2005-2006:

Officers:

Chair
Elliot Schrier
Vice Chair
Charmaine Eng
Recording Secretary
Doris Gilmore
Treasurer
Dave Russell

Directors:

Solna Braude
Linda Chen
Allan Daily
Bob Dens
Bill Holmberg
Viola Mays
Larry Naritomi
Phyllis Ng
Dean Prescott
Le Sotir

The above slate of Board Members and Officers and Directors will become effective November 1, pending comments from the membership.

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.

Board Members

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Elliot Schrier

Vice Chair:

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Dean Prescott

Le Sotir



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