

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

*September 2005*

**1170 Morse Avenue  
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## **PPSG Caregivers Luncheon**

*Charmaine Eng, Vice Chair, PPSG*

PPSG held its 2<sup>nd</sup> Caregivers Appreciation Luncheon on July 28<sup>th</sup> at the Biltmore Hotel in Santa Clara. There was a successful turnout with 81 participants. Chairman Elliot Schrier made the opening remarks and introductions of the guest speakers.

The caregivers heard a dynamic, informative and helpful talk given by Donna Schempp, LCSW, Program Director from Family Caregiver Alliance on the topic Caring for Yourself-Caring for Someone Else. She was followed by Marilyn Basham, PT, Outreach Coordinator at the Parkinson's Institute who spoke on "Tools and Tips for Caregivers" and offered many useful hints and massage therapy techniques for the attendees.

In addition to a Questions and Answers session, there was a discussion period where the caregivers had the opportunity to meet each other and to share their experiences. In another meeting room, Cheri Jackson, COO and her 6 outstanding staff members from the Older Adults Care Management of Palo Alto, conducted a separate program for PD patients

attending the luncheon with exercises and entertainment and special care.

Everyone had a choice of one of the following delicious entrees for lunch: Chicken Caesar Salad, Mahi-Mahi, Beef Teriyaki or Vegetarian Crepes.

There were reading materials given out by Boehringer-Ingelheim Pharmaceuticals, the Parkinson's Institute, Family Caregiver Alliance, Older Adults Care Management and California Telephone Access Program (presented by Love Miller, Field Representative).

The luncheon concluded with Cheri Jackson speaking on Caring for Caregivers, and a drawing for door prizes to 4 lucky winners.

By "supporting the supporters of Parkinson's patients," the caregivers, PPSG looks forward to sponsoring more Appreciation Luncheons in the future.

In addition to the guest speakers and organizations, a special "thank-you" to the following for their contribution to make this luncheon a success:

Solna Braude, Linda Chen, Viola Mays, Phyllis Ng, Marge Shively, & Le Sotir.

*The lovely 7/28 luncheon was enjoyed by all!  
Charmaine did a great job organizing this event.  
Thanks very much, Charmaine!*

**Avigen Announces Encouraging Early Data From Parkinson's Disease Clinical Trial - Evidence for First Successful Gene Transfer of AADC Gene in Humans**

July 19th - Avigen, Inc. today announced encouraging results from the first patient treated in a Phase I/II clinical trial of AV201, the company's drug candidate for the treatment of mid-to-later-stage Parkinson's disease. The results from positron emission tomography (PET) brain scans obtained six months after AV201 infusion indicated an increased activity of the gene product, aromatic L-amino acid decarboxylase (AADC) in the targeted area of the brain, compared with the patient's pre-treatment PET scans. These findings are consistent with increased dopamine production and transgene expression.

In Parkinson's disease, brain dopamine concentrations decline, causing the main symptoms of muscle rigidity, slow movements, difficulty walking, and poor balance. Levodopa, the first-line drug for treating symptoms of the disease requires AADC in order to be converted to dopamine. However, over time AADC production in the brain also declines as Parkinson's disease progresses, making levodopa less effective. The mid-to-later-stages of Parkinson's disease are often complicated by the toxic side effects associated with the higher doses of levodopa required to manage the disease's signs and symptoms.

AV201 is designed to restore the activity of AADC in the brain, thereby extending the therapeutic usefulness and life of levodopa while avoiding side effects.

The Phase I/II clinical trial of AV201 in Parkinson's disease was initiated in

December, 2004, at the University of California San Francisco (UCSF) and Lawrence Berkeley National Laboratory (LBNL). The study's Principal Investigator, Michael Aminoff, M.D., D.Sc., Director of the University of California-San Francisco Parkinson's Disease Clinic & Clinical Research Center, said, "This is an exciting beginning and a first for us: evidence of successful AADC gene transfer into humans. Most importantly for our patient, the procedure and gene appear to be safe. We're pleased with how well AV201 is being tolerated." Dr. Phillip Starr, neurosurgeon for the first patient in the study, added: "Based on the PET scans, it appears that the procedure and the use of convection-enhanced delivery to optimize the spread of AV201 worked as well as we could have hoped. We are enthusiastic about enrolling additional patients."

On April 5, 2005, Avigen announced that it will focus on the development of traditional pharmaceutical products, particularly small molecules and biologics. As part of the decision, the company indicated it would divest its proprietary AAV technology but was committed to ensuring the continuation of the ongoing clinical programs, including the AV201 Program in Parkinson's disease.

***Visit the PPSG Website***

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

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

## **Drug Used to Treat Parkinson's Disease May be Beneficial in Treating Fibromyalgia** - *New study finds improvement of fibromyalgia symptoms with few side effects*

*Amy Molnar*

28-Jul-2005 (EurekAlert) - The mechanism of fibromyalgia, a chronic illness characterized by muscle pain, fatigue, and sleep disturbances, is unknown, and medications used to treat it (such as antidepressants, antiepileptics, muscle relaxants, antiinflammatories, sedative hypnotics, pain relievers and nutraceuticals) have had limited success. New research findings indicate that the pain associated with this disease may be due to abnormal sensory processing in the central nervous system.

Recently, researchers from Pacific Rheumatology Associates in Renton, Washington, set out to investigate whether the dopamine receptor agonist pramipexole was safe and effective in treating fibromyalgia. Normally used to treat Parkinson's disease, this drug stimulates dopamine (a neurotransmitter) production by binding to dopamine receptor sites and is thought to inhibit sensory nerve-mediated responses. This is the first trial of pramipexole and only the second trial for this type of dopamine receptor agonist for the treatment of fibromyalgia. The findings are published in the August 2005 issue of Arthritis & Rheumatism.

<http://www.interscience.wiley.com/journal/arthritis>.

## **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 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**

At our last meeting, we heard from Sue and Allyson from Washington Hospital Speech Therapy Department. Those who attended the meeting were the recipients of an excellent and knowledgeable presentation. Our July 25 meeting featured Christy Casey, occupational therapist, Washington Hospital, Fremont. The subject was "Home Safety," a topic that would be of importance to all.

In August, we had our annual picnic instead of a regular meeting.

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 **510.494.4268**.

## 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, September 8** - Randy Hoffman, speech therapist at the Parkinson's Institute, will offer techniques of speech clarification.

**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

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

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> 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

**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

Our **September** speaker will be neurosurgeon Dr. Russell Andrews of Los Gatos Hospital, speaking on DBS.

Our **October** speaker, pharmacist Yui Hui, will talk on drugs for Parkinsons disease.

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**.

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

## 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.

Thanks to Redwood City Highway Patrol Commander Captain Bridget Lott for speaking at the May 20 meeting. She was most informative. Thanks also to David Shein of San Mateo for chairing the meeting. (Tom Constantino was attending a family university graduation out of town.)

For our June 17 meeting, we had some overdue administrative chores, a need to review our outside speakers, and plan for future guest speakers.

Our featured speaker for the July 15 meeting was Monica Volz, RN, MS. She is with the University of California Medical Center, San Francisco. She was welcomed by her friend and our co-chair David Shein.

There was no meeting in August.

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 the meetings.

## 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)

There were 10 of us there - 4 with Parkinson's, 6 caregivers or family. The discussion centered around 3 new people - the father who has PD, the wife and daughter who are caregivers. One caregiver brought a wooden staff to demonstrate how much better it is to stand up straight with a staff that is long enough. Often canes or walkers are so short the users have to bend over to use them. The members took the literature that explained the various terms referring to PD and we discussed the meaning of these in relation to the patients' bodies.

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 will be Carol Evans, Kaiser Hayward Parkinson's Nurse.

The speaker for the **October** meeting is 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**.

## 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 oquel 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 **Sue Croel** at **707.544.5151**, or **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 Sue Croel at 707.544.5151, or 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, call **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 **Donna Green (new leader)**, at **559.307.4189**, or the church office at **559.627.1660**.

## 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**

## Fight Caregiver Stress

While caring for a spouse or loved one can be rewarding, it can also raise stress levels. Chronic stress can lead to depression, hypertension, infectious illness and heart disease among caregivers. It is important that caregivers take care of themselves as well as the person with dementia.

In a long-term study of stress and health in older caregivers, Ohio State University researchers followed more than 100 caregivers of people with Alzheimer's and an equal number of non-caregivers. Focusing on interleukin-6 (IL-6), a compound in the blood that helps regulate immunity, researchers found that caregivers in the study had four times as much IL-6 as

non-caregivers, making them susceptible to diseases common among the elderly. The high levels of IL-6 did not ebb for years after caregiving stopped. The researchers noted that these effects might be multiplied if accompanied by unhealthy habits formed in response to stress, such as overeating, smoking or not exercising.

Here are some tips to help relieve stress:

- ✍✍ Ask family and friends to help with caregiving.
- ✍✍ Use an adult day care center or respite care for longer periods. It's good for both the person with dementia and the caregiver.
- ✍✍ Join a cyber support group or use online message boards and chat rooms, such as those offered by the Alzheimer's Association at [www.alz.org/login.htm](http://www.alz.org/login.htm).
- ✍✍ Care for yourself: exercise, eat well-balanced meals, take a daily multivitamin, and get enough sleep.
- ✍✍ Let your doctor know you are a caregiver-and don't skip your own checkups.
- ✍✍ Pray or meditate.
- ✍✍ Take time out: listen to music, read a book, call a friend, do something you enjoy.
- ✍✍ Call the Helpline, no matter the time of day or the day of the week (800-272-3900).
- ✍✍ For more on these strategies, contact the Chapter Helpline (800-2727-3900).

*This article was forwarded by Marge Shively.  
Thanks, Marge.*

## **Helpful Hints to Help with Living and Caring**

*By Nadine K. Grant*

My father had Parkinson's and was being fed with a G-tube when he was no longer capable of swallowing without choking, since he couldn't direct anything he swallowed down the right tube, and his

esophagus muscles failed to work to push the food down. This was exacerbated by the extra salivation caused by his taking L-dopa. Salivation required him to spit out the saliva or choke which was not pleasant to see.

When he had the G-tube inserted, we were concerned about his coming to the dining table due to the food smells, increasing salivation as well. However, if your table is like ours, the meal table is the social center, so we didn't want to deprive him of the social situation, including when we had guests over, as infrequent as that was due to the spitting. Therefore, we came up with a solution to the problem for a while. Go to the dentist and ask him/her for a bag of cotton "cylinders" used by dentists when filling your teeth to keep the area dry. The cotton absorbs the saliva when you put it in the mouth between the lower gums and cheek (a saliva point). Do it at the beginning of the meal and it will absorb a lot of saliva, reducing and sometime eliminating the coughing. It also is easy to remove and insert, even at the table.

**Word of caution:** Do not let the patient chew on the cotton. You have to be careful that they won't swallow the cotton.

### **Nadine K. Grant**

I'm a UC Berkeley grad, a third generation Japanese from Hawaii. After having been a software/systems engineer and technical manager in Engineering, Manufacturing and International Marketing and Sales at Fortune 500 companies, I left corporate America to be an international management consultant. What I do includes being an interim high-tech Chief Operating Officer (COO) and executive coach, especially helping companies deal with cross-cultural management issues.

Thanks to technology, being a consultant afforded me the time needed to fly home to Hawaii every other month to help my mom with the care of my father who was diagnosed with PD for 14 years. My cross-cultural knowledge also helped me to help my mother select a caretaker that she finally allowed us to hire when she

realized that her health was in jeopardy being over 80 years old. She was sleep deprived since she rolled him every 3-4 hours every night to insure that his lungs wouldn't get congested. It allowed me to interview caretakers from other cultures and help my mother adjust to them and vice-versa.

Being Asian, home-care was the only culturally viable approach. This was especially true since my father had gone blind and would've had a tough time adjusting to any type of new environment. It's something to consider when deciding what is needed.

In conclusion, we were faced with a difficult situation when my son was getting married last year. We had arranged for my mother to be able to attend by making arrangements for our regular caretaker to go to the respite care facility for the few days when my mother attended the wedding. My father passed away 3 weeks before the wedding so we felt that he was able to attend in spirit. It freed my mother from the worry about leaving him alone and guilt that she felt attending the wedding. It was my father's final gift to all of us.

**Another note of advice:** Please check to see if your PD patient is a Veteran. He might qualify for VA care and services. Besides providing inexpensive medication mailed to your home, they also provide lots of aids to make care-giving easier. The VA leased a hospital bed, provided an elevated toilet chair, bathing bench for the tub, and numerous medical supplies, including adult diapers. They also provided condom catheters and a suction machine to help suck out the mucus from the throat.

The shining star was the nurse who came to the home to check on my dad. She had been trained as a hospice care nurse and was a caring nurse with a wonderful sense of humor and life that provided my family glimmers of laughter and joy. She was also very knowledgeable on the resources available.

#### FOR SALE

**Fully accessible, 34-foot 1995 Allegro Bay Trailer.** Original owner, never damaged.

Custom designed for wheelchair accessibility, ideal for travel around the U.S. Side out Wheelchair lift, 28" door opening; accessible bathroom; 460 Ford "Super Duty Chassis;" set up for towing; under 39,000 miles; 2500 miles on new tires; gas/electric water heater, 2 years old; 7000-watt generator; awning; two TVs; built-in BBQ. \$33,000. Call 916-966-8754.

**Motorized wheelchair, Jazzy model 1133; Pride Mobility Corp**

([www.pridemobility.com](http://www.pridemobility.com)); one year new; all manuals and accessories included. Call 925-933-6679 for asking price and more information.

If you have any **items for sale or donation**, such as exercise equipment, wheelchairs, etc., please write to PPSG, call us at 408.734.1593, or e-mail [pmsginfo@yahoo.com](mailto:pmsginfo@yahoo.com).

## 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 **1:30 and 3:30 PM** at the Parkinson's Institute in Sunnyvale. The next 2 board meetings are September 21 and October 19. To confirm meeting dates and time, please call us at 408.734.1593.

## New Board Member

Congratulations to **Dean Prescott**, who joined the Board of PPSG recently. Dean is the support group leader of the Los Altos-YPSG (Young Parkinson's Support Group). Welcome, Dean!

## **Who Am I? -In Defense of The Real Me**

*By Phyllis Bunnelle, a Sunnyvale SG Member*

When you look at my face or hear my name, who do you think I am? As my body has changed and is no longer what it used to be, do you think I, too, have somehow changed? If so, who do you think I am?

As my face may not show my true feelings, as I cannot write by hand, and as I'm losing my ability to talk or otherwise express myself, I can understand your dilemma and I owe it to myself to tell its story while I can still manage my computer keyboard, as that's my only remaining avenue for in-depth communication

I was first diagnosed as having Parkinson's disease, and now I agree with the doctor who in 2003 said I have StriatoNigral Degeneration (SND), which is a form of Multiple System Atrophy, an atypical Parkinsonian disease known as MSA. MSA is described as a progressive neurodegenerative disease caused by degeneration of nerve cells in specific areas of the brain, which then cause problems with movement, such as stiffness or rigidity, slowness in movement (bradykinesia), disturbances of walking, posture, balance, and coordination, including speech, and a wide array of autonomic functions of the body, such as bladder and bowel control and swallowing – hence the label “multiple system atrophy.”

After my diagnosis at age 72, we were quickly forced to give up enjoying our “golden years” as my body reverted to what I consider its “baby stage.” Like a baby, I came to depend on 24-hour care as I became unable to do things like lift my head from my pillow, sit up or turn over in bed, brush my teeth or feed myself. That list continues to grow as other things descriptive of an infant are added – the latest being losing my ability to talk. My problems with eating and drinking are complicated and constantly changing. It feels like there is a continuous

battle between my brain and my body over control of my bladder.

Decidedly the most frustrating of my symptoms is the breakdown of my ability to communicate. To get the most from my doctor's appointments, I give them a typed report containing a list of my current medications, plus comments about my condition and complaints. Preparing this in advance guarantees I say what I want to say the way I want to say it. My husband, Phil, takes good notes during the visit which he later types up for me.

The written word means a lot to me. I have written 37 books, which are in a number of libraries, both here and in Europe, and numerous articles which appear in various publications. I published my first book in 1980 and I just finished my latest book containing 161 pages a few weeks ago. While I now need to use the hunt-and peck system to write the text, it is becoming more difficult to maneuver the mouse. Although I've finished my research, the books are a lot of work to compile and print for publication. Phil and my caregivers are great help.

.....

In closing, I would like to say that whenever my ailing body takes over, I pray that I will be I remembered for my sharp mind, strong drive, and giving nature that enabled me, with Phil's moral, technical, and financial support, to give the world so many history books that will continue to live on long after I am gone.

I summary, I'll list a few thoughts about who I am:

- Just because I'm sitting down – doesn't mean I'm sitting on my ears. I can hear you.
- Just because I don't join in a conversation – doesn't mean I'm not interested in what's being said.
- Just because I don't give my opinion – doesn't mean I don't have one.

- Just because I'm not as social and don't attend the activities I used to – doesn't mean I don't want to.

-Just because I'm not smiling on the outside – doesn't mean I'm not smiling on the inside.

- Just because I don't wear the latest fashions – doesn't mean I'm not interested in what you're wearing and looking and smelling nice myself.

- Just because something appears too difficult or impossible to do – doesn't mean I won't try.

- Just because I read everything I find about my disease – doesn't mean I agree with everything written.

Just because there's no help for me now – doesn't mean there won't be one in the future.

*Phyllis and Phil Bunnelle are members of the Sunnyvale support group. Phil is a Berkeley trained engineer and Phyllis is an author who has written many interesting books on genealogy. Phil always brings KFC Fried Chicken to the monthly potluck and therefore earned his nickname: "The Colonel."*

### **Disclaimer**

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### **Press Release**

## **BrainStorm Cell Therapeutics Announces Adult Stem Cell Breakthrough for Neurodegenerative Diseases - Differentiation into GDNF-Producing Astrocytes**

NEW YORK & TEL AVIV, Israel-- (BUSINESS WIRE)--July 18, 2005-- BrainStorm Cell Therapeutics (OTCBB:BCLI - News), today announced a breakthrough in the development of adult stem cell therapeutics for neurodegenerative diseases. The company's scientific collaborators at Tel Aviv University, have successfully used adult stem cells to produce glial derived neurotrophic factor (GDNF). GDNF producing cells hold great promise for treatment of Parkinson's and other neurodegenerative diseases.

In the current study, the research team at Tel Aviv University used proprietary technology, to differentiate human bone-marrow-derived mesenchymal-stem cells into neural supporting cells that produce GDNF. Worldwide rights to these research results are exclusively licensed to BrainStorm.

GDNF has been shown to protect dopaminergic brain cells, neurons that produce dopamine that becomes depleted in Parkinson's patients. GDNF has also been shown to have a beneficial role in protecting neurons in animal models of Amyotrophic Lateral Sclerosis (ALS) and Spinal Cord Injury (SCI).

Source:

<http://biz.yahoo.com/bw/050718/185362.html?v=1>

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