

Parkinson's Patients Support Groups, Inc.

Feb./Mar. 2006

**1170 Morse Avenue
Sunnyvale, CA 94089-1605
www.ppsg.org 408.734.1593**

Editor-in-chief: Phyllis Hsu Ng

Articles Editor: Ann Roper

Webmaster: Solna Braude

Editorial Staff:

Linda Chen

Charmaine Eng

Viola Mays

New Caregivers Support Group At San Francisco VA

Caregiving for loved ones with Parkinson's disease is an evolving and demanding responsibility. If you are a partner caring for a loved one with Parkinson's disease, we invite you to our new monthly support group held at the Veterans Affairs Medical Center, San Francisco. We meet to discuss 'care issues' in a safe and confidential environment and share how to better manage, cope or intervene for support and to improve ability to care.

When: One Thursday each month, 12:00 noon to 1:00 p.m.

Dates: January 19; February 9; March 16; April 6; May 11; and June 15.

Where: VAMC Parkinson's Disease Center Conference Room
Building 203, first floor (one floor up from ground level), Room 1B26A

Group Leaders will be **Susan Heath**, RN MS, PADRECC Clinical Nurse Specialist and Aliza Benditsky, LCSW, Social Worker for Neurology/Neurosurgery. Please call **415.379.5530** to RSVP for each session.

World Parkinson Congress

February 22 – 26, 2006
Convention Center, Washington, DC

Registration Fee: \$100.00 per person
Visit www.worldPDcongress.org to download a form for fax or mail registration. The WPC preview program is now online for an overview of the conference activities. You will also find information on housing, programs, speakers, and more.

If you or someone you love has Parkinson's disease, or if you are caring for a person who has PD, consider making plans to attend this first World Parkinson Congress and learn about the latest science, treatments, and care. Thank you for your interest and support. The WPC organizers realize that the costs of attending a conference, including hotel and travel, can be beyond the average budget. This is why they have worked to keep costs down for patients and caregivers, with a registration fee -- for all four days -- of only \$100. Rooms have also been reserved for attendees who book by January 23, 2006.

For details, visit www.worldPDcongress.org and reserve your spot!

Adapted from www.PDtrials.org

“Engineered” Stem Cells May Help Treat Parkinson's

They are able to penetrate the brain's blood barrier, researchers report

Robert Preidt

Dec. 15 (HealthDay News) -- Engineered human progenitor brain stem cells are able to produce and deliver into the brain a growth factor that shows promise in treating Parkinson's disease, say researchers at the University of Wisconsin-Madison.

A major challenge in treating Parkinson's and other neurodegenerative brain disorders is getting drugs to the desired areas of the brain. The brain's structure effectively blocks the delivery of most drugs via the bloodstream. The engineered progenitor brain cells are designed to sneak drugs past the blood-brain barrier.

The University of Wisconsin team obtained and grew large numbers of progenitor cells from human fetal brain tissue and engineered those cells to produce the growth factor called glial cell line-derived neurotrophic factor (GDNF).

Some small clinical trials showed that GDNF provide relief from the debilitating symptoms of Parkinson's disease. However, GDNF could not cross the blood-brain barrier and had to be pumped directly into the brains of Parkinson's patients in order to work.

In this latest study, researchers transplanted the engineered progenitor cells into the brains of rats and monkeys. The cells effectively integrated into the brains of the animals and delivered GDNF to the targeted brain areas.

The findings were published in the Dec. 15 issue of the journal *Gene Therapy*.

"This work shows that stem cells can be used as drug delivery vehicles in the brain," University of Wisconsin-Madison neuroscientist Clive Svendsen said in a prepared statement.

SOURCE: University of Wisconsin-Madison news release, Dec. 15, 2005

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

Swallowing Difficulties

People with PD have swallowing difficulties (Dysphagia). The first symptom is often choking on water or bread. If one develops swallowing difficulties, preparing meals and eating will require time, thought and effort. Weight loss is a frequent side effect of swallowing difficulties. Not consuming adequate calories to maintain your weight will make one feel tired and at risk of developing malnutrition.

Tips for safer swallowing:

- ✍✍ Eat in a pleasant, relaxing environment.
- ✍✍ Sit up straight, so gravity helps food go down. Position your head slightly forward with chin down to help prevent food from going down an airway.
- ✍✍ Try to keep the plate in line of your vision.
- ✍✍ Experiment with different plates, cups, glasses and utensils.
- ✍✍ Do not breathe until you have completely swallowed.
- ✍✍ Eat slowly taking small bites and chewing food thoroughly.
- ✍✍ Concentrate on swallowing, avoiding distractions such as radio and television.
- ✍✍ Swallow all the food in your mouth before taking more.
- ✍✍ Cough when you need to in order to prevent food from going down the airway.
- ✍✍ Never eat alone. A family member should be trained in the Heimlich maneuver.
- ✍✍ Rinse your mouth after eating.
- ✍✍ Sit in an upright position for about 30 minutes after eating.

Calorie-boosting suggestions:

- ✍✍ Add butter or margarine to hot foods. A teaspoon adds 45 calories.
- ✍✍ Increase calories in food by using gravies, cream or cheese sauces, salad dressing or mayonnaise on meats, vegetables and starches.
- ✍✍ Powdered coffee creamers add calories. Add them to gravy, soup, milk shakes and hot cereals. **Make sure to stir well.**
- ✍✍ Add jelly, jam, honey or maple syrup.

- ☞ ☞ Drink fluids with calories and nutrients such as juice and milk. Water, black tea and black coffee have no calories, regular soda is high in calories, but is lacking in all nutrients.
- ☞ ☞ Drink Carnation Instant Breakfast, Ensure, Boost or Resource. (Don't drink these when you are taking your Sinement.)
- ☞ ☞ Eat yogurt, pudding or applesauce.
- ☞ ☞ Season soft or pureed foods.

Preparing food in a blender:

- ☞ ☞ If soft, solid food is too difficult to swallow, you may need to use a blender or food processor to prepare meals. The food should form a smooth mass that will not separate in the mouth. It should be moist enough so that it slides down the throat. You may need to strain the food before it is eaten.
- ☞ ☞ To fix foods in a blender, use liquids with flavor such as soup, fruit juice and milk. Also, try cream sauce, gravy and salad dressing.
- ☞ ☞ If foods fixed in a blender are too thin, add a thickening agent such as a commercial thickening powder, flaked baby cereal or mashed potato flakes.
- ☞ ☞ Use unflavored gelatin as another type of thickening agent.
- ☞ ☞ For fiber, eat fruit such as applesauce, banana, pears and peaches blended to the safest consistency.
- ☞ ☞ Season your food with herbs and spices.
- ☞ ☞ For convenience, purchase pureed baby foods, which you may need to thicken with a thickening agent and season to taste.

Managing saliva secretions:

There are problems with saliva secretions that may affect people with swallowing difficulties, accumulation and thickening. Normally, one swallows saliva unconsciously. With PD one must remember to swallow, or saliva will build up. The saliva may also be thicker and thus, harder to swallow.

- ☞ ☞ Remember to swallow frequently, but slowly and carefully.
- ☞ ☞ Avoid very sweet and very sour foods, because they may stimulate salivary glands.
- ☞ ☞ Use a suction machine if needed.
- ☞ ☞ Increase the fluid in your diet to thin your saliva.
- ☞ ☞ Maintain good oral hygiene.
- ☞ ☞ Try drinking club soda.
- ☞ ☞ Use a humidifier.
- ☞ ☞ Try papaya or pineapple juice.
- ☞ ☞ Ask your physician about anticholinergic agents.
- ☞ ☞ Do not use tobacco.

Adapted from Saint Louis Parkinson Newsletter, #4, 2005.

New Findings - Most people think of Parkinson's disease as something that leads to a shuffling gait or uncontrollable tremors in the hand. But Parkinson's can also trigger anxiety and other psychological disorders, and – as scientists learned this year – so can the treatment. A Mayo Clinic study found that in rare cases, treatment with a so-called dopamine agonist led 11 patients to develop compulsive gambling habits (two reported losses over \$60,000). Four had never gambled before, but all the patients stopped their wagering within months after treatment was discontinued. The effect was apparently greatest with the drug pramipexole, which investigators theorize indirectly triggered the “reward system” of the brain. Fortunately, the urge to gamble didn't seem to show up in folks who took only took the major Parkinson's drug, carbidopa, to slow its effect.

Harvard researchers found that vigorous regular exercise early in adult life cut in half a man's risk of developing Parkinson's later on. Physical activity was also associated with a decline in Parkinson's in women, although the drop was not statistically significant. Still, there are plenty of other reasons – from helping the heart to improving one's mood – to get moving.

Edited from Time magazine, December 5, 2005 issue; forwarded by Allan Daily. Allan is a PPSG Board member. Thanks, Allan!

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

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

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

January 24: Susan heath, RN, SFVA, "The non-motor symptoms of Parkinson's disease."

February 28: Xianmin Zeng, PhD, Buck Institute. "Update on Parkinson's Research."

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: the group has merged with Early Onset Support group, so there will be **NO MORE 2nd Monday meetings**. Contact **Margy Hansell** at **925.939.4210**.

Early Onset Support Group: Meets on **3rd Saturdays** from **10 AM-noon**. For meeting location, 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.

The January meeting featured Marilyn Basham, Physical Therapist from The Parkinson's Institute.

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 Jose – Almaden/Blossom Valley

The group is currently taking a break from meeting pending increased membership. 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

On January 6, the S. J. Support Group met at St. Francis Episcopal Church for their first meeting of the new year, with 43 people in attendance. The subject of this meeting was group discussions, in which the Parkinson's patients were seated in the hall and the caregivers were taken to another room. The lively discussions which followed show that these people are friendly and at ease with each other, wanting to talk about their common problems with this terrible disease. This is a very worthwhile type of meeting and occurs several times a year. Our attendance has increased quite a bit because one of the former caregivers takes the time each month to call and remind of the meeting and what the program is about. We wouldn't be able to do all this if it weren't for **Joan Lorentson** and **Celia Provax**, to name a few. They are real life savers!

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

Our February 8 meeting featured Karen Roth, nutritionist from Mountain View Kaiser. Her topic was "Nutrition and Parkinson's."

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

The January 6 meeting featured Attorney Sarah Shena, Kings/Tulare Area Agency on aging. The topics were Durable Powers of Attorney for Health Care, Living Trust, Wills, etc.

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**.

Visit the PPSG Website

www.ppsg.org

Implanted Eye Cells Eased Parkinson's

Andrew Stern

December 19, 2005 (Reuters Health) - A handful of people with Parkinson's disease showed marked improvement after surgeons implanted in their brains chemical-producing cells taken from the eye of a dead donor, researchers said last week.

Cells from the inner, or pigment, layer of the eye's retina make levodopa, which Parkinson's patients commonly take in pill form to replace lost production of the neurotransmitter dopamine.

Dopamine allows the brain to control the body's movements.

For most patients, levodopa pills lose their effectiveness within five years, and larger and larger doses are needed to curb the involuntary movements and shaking symptomatic of the disease.

Many people on the drug develop involuntary writhing or dance-like movements.

The retina cells were cultivated and implanted in the brains of six patients with advanced Parkinson's, researcher Natividad Stover of the University of Alabama said.

One year later, the patients scored 48 percent higher on tests of movement and coordination, and the improvement was sustained after two years, Stover wrote in the journal Archives of Neurology.

"The implants were well tolerated," the report said. Improvement was also observed in daily living and quality of life.

Some scientists have viewed implanting fetal stem cells into the brains of Parkinson's patients as a promising avenue to restoring dopamine production. But preliminary human trials were disappointing, and animal experiments have yielded mixed results.

Other treatments showing promise include deep brain stimulation with implanted electrodes, drugs that promote brain cell growth, and gene therapy.

The researchers said a larger study has been started to test the efficacy and safety of retina cell implants.

The two articles on this page are researched by Linda Chen. Linda is a PPSG board member as well as the Palo Alto Support Group leader. Thanks, Linda!

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.

CU Finds How Gene May Help For Parkinson's Fight

Bill Scanlon

December 29, 2005 (Rocky Mountain News) - Colorado researchers have uncovered how a gene linked to Parkinson's disease can keep brain cells alive.

The discovery could lead to new drugs to spur the gene into acting properly and stopping Parkinson's disease at its earliest stages.

Researchers at the University of Colorado at Denver and Health Sciences Center performed a detailed analysis of the gene DJ-1. They found that when DJ-1 is functioning properly, it can prevent dopamine cells in the brain from dying.

When DJ-1 is abnormal, it can lead to nerve degeneration.

Parkinson's disease occurs when dopamine cells in the brain die or are damaged.

That makes it difficult for the brain to transmit messages to the body to make movements. Boxing legend Muhammad Ali and actor Michael J. Fox are among the celebrities who have the disease.

CU researchers found that when the DJ-1 gene was over-expressed - that is, more copies than normal - in dopamine cells, the cells were protected from different kinds of chemical stress. That demonstrated that the gene plays an important role in keeping dopamine cells healthy.

When there is an ample supply of DJ-1, the gene can spur the making of a helpful antioxidant to combat oxidant stress, or turn on the production of a protein that helps clean up abnormal proteins.

"Our research shows how a genetic cause of Parkinson's disease works," said Dr. Curt Freed, division head of clinical pharmacology and toxicology at the CU School of Medicine. He is co-author of the study that will appear in Friday's issue of the Journal of Biological Chemistry.

"We show how the normal function of the gene keeps dopamine cells from dying," Freed said. "If the gene is abnormal, these protective mechanisms cannot be brought into play. "DJ-1 is the third gene that has been linked to Parkinson's disease. Eleven different mutations have been found in the gene, suggesting that loss of DJ-1 function leads to neuro-degeneration," said Wenbo Zhou, assistant professor of clinical pharmacology and toxicology at the CU School of Medicine, who was the lead investigator of the study.

Board Members	Directors:
Chair: Elliot Schrier	Solna Braude Linda Chen
Vice Chair: Charmaine Eng	Allan Daily Bob Dens
Recording Secretary: Doris Gilmore	Bill Holmberg Viola Mays
Treasurer: Dave Russell	Larry Naritomi Phyllis Ng Dean Prescott Le Sotir

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.

Mark Your Calendars – May 18, 2006

The Parkinson's Institute and the Neuroscience Institute at Stanford Present "**Help for Today, Hope for Tomorrow,**" The 10th Annual Outreach Symposium for Parkinson's patients and their caregivers. Registration opens March 15. More details in upcoming newsletters. For more information, call the Parkinson's Institute at **408.542.5619**.

The Parkinson's Action Network (PAN) 12th Annual Forum: **Feb 19-21, 2006 Washington DC**
For detailed information about registration, log on to www.parkinsonsaction.org***



Parkinson's Patients Support Groups, Inc.
1170 Morse Avenue
Sunnyvale, CA 94089-1605
408.734.1593

ADDRESS SERVICE REQUESTED

Non-Profit Organization
US Postage
PAID
Sunnyvale, CA
Permit No. 779

February/March 2006