

Parkinson's Patients Support Groups, Inc.

February 2005

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The Parkinson's Institute
Presents

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& Their Caregivers

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

California Passes Landmark Bill to Find a Cure for Many Chronic Illnesses

By Leonard Ke

Thanks to you, California passed Proposition 71, the California Cures initiative that provides the funds necessary to gain a foothold in the fight against uncured chronic debilitating diseases, including Parkinson's. Specifically, it mandates that California will make available \$3 billion for embryonic and adult stem cell research. While there are concerns about the large amount of money being spent, we can also view this as an *investment*. Consider these numbers: California has 130,000 people who have a chronic illness caused by a yet uncured disease. The costs for managing their illnesses run to \$110 billion per year. Nationwide the cost is over \$1 trillion. By finding a cure for one of the diseases, the revenues gained could pay off the debt. In fact, the picture looks better when we take a more comprehensive look. California's economic revitalization effort will be given a boost by the infusion of this capital into the economy. Medical research organizations are looking for new office space, employees, and lab equipment. The positive response we

gave to Prop 71 has gained the attention of many lab researchers around the nation who have had their career goals put on hold. They now see California as a desirable place to work and are being recruited to work here. So instead of being affected by a "brain drain," California has the position of being able to pick the "best and the brightest" talent out there, and that should bring about positive results soon, and establish California's world leadership in this vital area. And as the expected new therapies are sold to patients, licensing agreements will return a share of the profits back to the state.

Just as important as the numbers is the expectation of improved quality of life for people who suffer from diseases that will be cured or greatly alleviated by this research. To that end, a member of the Parkinson's community will be given a seat on the California Institute for Regenerative Medicine that allocates funding and research priorities. We can be assured that the finest minds will be supported in finding a cure for Parkinson's.

So please congratulate yourselves for being involved in what will be recognized as a turning point in medicine, a revolutionary moment in human history.

For more information, go to the Yes on 71 website at:
<http://www.curesforcalifornia.com/>

Leonard Ke is the leader of the Daly City support group. Leonard spends lost of time and energy in many volunteering activities. Thanks so much, Leonard!

When Does Life Begin?

By Clement Butt, M.D.

The controversy over stem cell research keeps being brought up again. It is understandable, because it has political, biological, and spiritual or ethical ramifications. The answer lies in when life exists. When do we decide the termination of the state of pregnancy as abortion or killing? Does life begin at conception, three months, six months, or at the time of birth?

Before we define life, we have to know that the life we talk about has to be comparable to the life of similar species. For example, two persons have all the organs of a living man. One is dead and one alive! How do we know which is which? One may quickly point out the dead person's lack of spontaneous breathing and heartbeat. However, the dead person's organs may still be alive and be transplanted into another person's body. While the person as a whole is pronounced dead, the organs may stay alive. Death of a person has to be compared to another person as a whole and not an organ and not a cell. In other words, death or life is specie specific. If two subjects have the same organs and one shows signs of life, perhaps with assistance, and the other cannot make any effort at all to function as a human being, the former will be considered alive and the other one not.

In this age of high technology, let us use a computer for illustration. When do we think a computer is functioning? Without power supply, the computer, no matter how sophisticated it is built, is not a live computer. The question is what are the minimum components essential for

the computer to function when power is available? Power is always there. The determining factor is the minimal requirement of the essential parts for the computer to function. That is when life begins with the computer.

It is the same with human life. Life force is always there. It is neither created nor can it be destroyed. Until the human body has all the organs ready to survive, to function spontaneously and strongly enough to sustain life and all its activities, even perhaps with artificial support, life has not begun in that baby. If any stage before that is considered as killing a life, then cutting hair would be considered killing too, since we are violating a hair cell. However, compared to another person, cutting hair would not qualify the definition of death in the same species. It is not murder for that action.

Since artificial measures are used to increase the chance of survival, does it mean that the definition of life becomes a function of our healing skill? Of course not, the minimum presence of functioning organs to sustain life remains the same.

I am for stem cell research but I am not in a hurry to apply it to clinical use yet. The research nowadays seems to hinge on finding the proper technique to implant the cells and not so much on finding out how they work. I believe we should devote a lot of time to fundamental research to understand how the stem cells behave, more so than its empirical clinical application.

Dr. Clement Butt and his wife, Sushih, are members of the Sunnyvale support group. Clement regularly shares his 20-plus-year Tai Chi experience with fellow member; he also

teaches us special hand exercises to help coordination. We all learn from his many interesting "steps." Thanks, Clement!

Fox, Michael, *Lucky Man*

By Thomas L. Constantino
Co-chair, Redwood City support group

It began with tremors in his left hand. He thought it was shakes from too much beer. It was years of denial before he admitted he had a degenerative, incurable neurological disorder.

New York Times bestseller *Lucky Man* is television/film's Michael J. Fox's autobiography of his battle with Parkinson's disease (PD).

Fox is best known for his *Family Ties*, *Back to the Future*, and later *Spin City* television series, and movies. Concerned about being out of shape, he cut back on alcohol and started jogging. But a 5-mile loop at Martha's Vineyard exhausted him. The left side of his body wasn't moving. His arm wasn't swinging. His wife, actress Tracy Pollan, was shocked at his appearance and urged him to see a doctor back in New York. At the end of his second treatment the physician referred him to a neurologist friend.

Michael J. Fox was not prepared for the two words the neurologist hit him with that day, "Parkinson's disease." He remembered words like young onset, progressive, degenerative, incurable, very rare at his age, new drugs.

They hugged and cried when Michael told Tracy. (My wife Susan and I responded identically when I was diagnosed with PD in 1999 at 55 years of age.) Outside of his family and very closest of friends and associates, no one

knew. This is how matters stood for seven years.

Michael grew up on Canadian Forces bases, principally in British Columbia. His father, Sgt. William Fox, was a communications NCO. He was a police dispatcher in his post retirement job.

In grammar school Michael enjoyed writing and ice hockey, a rite of passage for boys in Canada. He had a mild affinity for acting in high school. Memorizing lines came easily. He drank up laughter and attention in high school plays. He appeared in every school production. While still in high school he picked up community acting jobs, commercials, radio work and guest spots on Canadian television series and earned \$6,000 – more than his dad’s salary.

With a running buddy, he visited Disneyland and Southern California. At the same time he was flunking high school drama for too many absences, he was performing nightly in a long-running Vancouver play. He quit school and his life in Canada in the eleventh grade and headed to Hollywood. His father accompanied him on the thousand-mile drive south on I-5.

Michael found California to be everything Canada, with its polite provincialism and reverence for order, could never be. At first he earned a minimum salary, could barely afford a one bedroom apartment, and failed to save for state and federal taxes. He had two words for auditions, *they suck*. He was insecure about his height. Pacific Bell cut off his telephone service. Soon his parents were urging him to come home.

His break finally came with *Family Ties*. NBC loved the plot, ordering thirteen more for the fall season. By its third season *Family Ties* finished number two in the Nielsen ratings. It was a hit. Michael started receiving movie offers. With *Family Ties* the second most-watched program in prime time, *Back to the Future* shot to number one at the box office.

When Michael received his first Emmy in 1986 he bounded up to the stage and said “...I feel four feet tall.” He had come a long way. Yet by the fall of 1991 Michael J. Fox was seeing one of the prominent neurologists in North American, a renowned figure in the treatment of PD. The signs of the disease were there: diminished blinking, reduced spontaneity of facial expression. No longer was he the final authority over his body movements. Parkinson’s disease, sometimes called shaking palsy, usually begins between 50 and 65 years of age. The third opinion confirmed Michael’s PD.

Researchers have not yet found the exact cause of Parkinson’s. There is a gradual reduction in the amount of dopamine manufactured by the brain. Drugs such as Sinemet (carbidopa-levodopa) improves mobility and allows patients to function almost normally. With larger doses one risks debilitating side effects like dyskinesias – involuntary movements. With pills, PD could be hidden. One physician told Michael that he had ten good years of work ahead of him. He had just turned 30! There is never a good time to find out that you’re incurably ill.

Michael first learned that it was possible to live a life without alcohol.

And although he accomplished great things in life without ever graduating from high school, this had always bothered him. At the tender age of 31, with his son registered to begin kindergarten, Michael applied to take the General Equivalency Diploma test. He breezed through the five-part GED exam.

Tracy and Michael reside in New York and spend their summer months split between their farm in Vermont and home on Martha's Vineyard. Twin daughters joined the family early in 1995. Within three years Michael was scheduled for brain surgery to eliminate the tremors on his left side. (This surgery does not alleviate rigidity, shuffling, and balance issues.)

Michael finally went public with his PD. He soon heard from other public figures who had been diagnosed with Parkinson's including Billy Graham, Muhammad Ali, and Janet Reno. His growing involvement in Parkinson's advocacy work followed. By 1999 he was appearing before Congressional hearings. The issues were the adequacy of federal funding for Parkinson's research and stem cell research.

Lucky Man is a very personal account of Michael J. Fox's decade long battle with Parkinson's disease. Profits from this 2002 book are being donated to the Michael J. Fox Foundation for Parkinson's Research. Visit the website at michaeljfox.org.

Note: It took three days to get *Lucky Man* through Kepler's Bookstore in Menlo Park, CA, telephone 650-324-4321, www.keplers.com. Tom Constantino is a trustee emeritus of the San Mateo County Community College District.

Berkeley

The group meets on the **3rd Monday** of the month at the Northbrae Community Church. The address is 941 The Alameda, Berkeley, and the meeting time is **10:00 AM-12:00 noon**.

For information, call **Mitzi Cahn** at **510.527.9075** or **Irene Smythe** at **510.524**.

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

At our November meeting, we renewed old acquaintances by having Dr. John Ribaldo as our guest speaker, since he was one of our first. His presentation was brief and to the point, and allowed ample time for answering the many questions that our members had. We appreciate his taking the time to talk to our group.

Our Christmas dinner was an outstanding event catered by Minerva's. Their food service provided us with a great number of choices.

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 **510.494.4268**.

Magnolia-Peninsula

Thursday, February 10

Dr. Helen Bronté-Stewart, nationally known neurosurgeon of Stanford, will field any and all questions related to Parkinson's and other movement disorders.

No meeting in March!

Thursday, April 14

Hazel Horsnell and some of her colleagues will demonstrate various methods of Massage Therapy. This will be a unique "hands-on" session.

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 and Magnolia Avenues, as well as Chadbourne.

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**.

Monterey

We meet at 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
Pleasanton. at Senior Center, 5353 Sunol
Blvd., For information call **Cliff Terry**
at **925.935.1772**

Oakland

On December 2 Carol Evans, a nurse
practioner with a specialty in
Parkinson's disease, explained the nature
of the condition, and the whole gamut of
treatments presently available and
possibly available in the future. She led a
lively question and answer session.

Our January 6 meeting was led by
Robert Lemon, assisted by Christi
Borge, on the topic of ways to simplify
daily challenges for people living with
Parkinson's. The American Parkinson's
Disease Association (APDA) offers 34
ways in their 2005 calendar. Our
members added several more of our
own.

Our February meeting featured Dr.
Roshan, who does meticulous research
on the effect of Sinemet on the speed
and accuracy of complicated motor
responses. She also explained how this
seemingly irrelevant study might
contribute to an eventual deeper
understanding of the disease.

In our March 3 meeting, Dr. Rhoda
Agin will show us how we can improve
our voice volume and quality so that we
may speak more effectively and
attractively. This helps Parkinson's
patients to have better social
relationships and enables them to
express themselves more effectively.

**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**.

Palo Alto

*(for Spouses and Family Members of
Parkinsonians)*

The Palo Alto Support Group for
Spouses and Family Members of
Parkinsonians usually meets on the **3rd
Friday** of the month, from **11-12:15**, in
the Garden Room of Avenidas Senior
Center, 450 Bryant Street, Palo Alto. For
meeting information call **Linda Chen**, at
650.254.0906. **For directions, call
650.326.5362**.

Redwood City

On January 21 Tracy Stewart, RN, of
the Parkinson's Institute, made a return
appearance with our PPAP group. Tracy
was last with us a year ago.

Tracy is the Coordinator of Clinical Trials at the Parkinson's Institute. She discussed Apomorphine and other new drugs expected to be out this year.

Thanks again to Al Reichert, Manager of Sequoia's Sleep Disorders Center, who spoke at our October meeting. Since there were so many questions, by popular demand Al will be invited back later this year.

We hope you all had pleasant and joyful Thanksgiving, Hanukkah, Christmas and New Year's holidays. Our January 21 meeting was the first since Ray Lang's retirement. Ray was in the chair for five years! Wow! Ray, you have all our thanks for a job well done.

PPAP-Positive People Against Parkinson's-meets on the **3rd Friday** of each month, from **12:30 to 2:00 PM**, at Sequoia Health and Wellness Center, 702 Marshall Street, Redwood City. Parking available in the rear. 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 free for this meeting!) For meeting tie, call **Tom O'Brien** at **415.352.6514**.

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. Francisco Episcopal Church, 1205 Pine Avenue, San Jose. For information, please call **Charmaine Eng** at **408.723.8116**.

San Leandro

The group meets on the **1st Thursday** of the month, **except summer months**, at **10 AM**, at The Education Center of San Leandro Hospital, 13855 East 14th Street, San Leandro. For information, please call **Roy Burnham**, at **707.781.3308**.

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'

Parkinsonian sessions. They are divided so that each one has 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 guest, 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 or Ron Trowse.

Sunnyvale

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

Turlock

The group meets on the **1st Thursday** of the month, from **2-3 PM** at Emanuel Hospital, Delbon Street, Turlock. For further information, please call **Marion Johnson** at **209-634-3157** or **Jean Okuye** at **209.394.2421**.

Tulare-Kings

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 **Mary Dickerson**, at **559.622.9044** 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 **2PM**, 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**.

YPSG

The Young Parkinson's Support Group meets on the **2nd Saturday** of the month at the First Presbyterian Church of Los Altos, at the intersection of Miramonte Avenue and Foothill Expressway, from **10:00 AM to 12 noon**, at the Golden Oak meeting room. For more information, please call **Dean Prescott** (the group leader) at **408.738.2505** or **Dick Lacey** at **650.328.3429**.



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