



Parkinson's News Network

Volume 1, Issue 1

December 2002 Newsletter

Contact Information:
Sridevi Sheshradri
 Center Coordinator
 Phone: (866)250-2414
 Email: sridevi@stanford.edu
 APDA Information &
 Referral Center
 300 Pasteur Drive
 Room A-343
 Stanford, CA 94305-5235

"Although it is a relatively new type of treatment, Deep Brain Stimulation offers Parkinson's patients new hope in overcoming the suffering often associated with the illness."

Caregivers: Approaching Parkinson's	2
Ask the Doctor: Coenzyme Q10	3
Open Doors	4
History of Parkinson's	5
Resources	8

Symposium on Medical and Surgical Treatments for Parkinson's Disease

Saturday, Oct. 26th, 2000
 Stanford University Medical Center



Gary Heit, M.D., Ph. D. discusses a promising treatment for Parkinson's.

"Welcome, we're glad you're here.

We invite you to use our services in any way you can." With these words, John Amber welcomed the guests at the symposium on Medical and Surgical Treatments for Parkinson's Disease, which was hosted by the Stanford Medical Center. The symposium was meant to provide patients and caregivers with valuable information about the multitude of resources available to them. Mr. Amber, assistant director of the APDA Regional Office, clearly had this purpose in mind. In fact, he encouraged patients, relatives of patients, and caregivers to visit the Stanford Medical Center. He wanted to ensure that everyone in need of aid or assistance would receive it, and he proudly explained that the Stanford Medical Center, being "one of the best hospitals in the nation" according to the *US News and World Report*, would be happy to provide any help it can.

Stewart's Remarks:

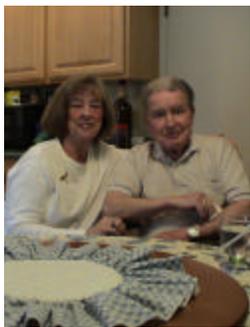
Following Mr. Amber was Dr. Helen Bront? Stewart, MD, MSE, director of the Stanford Comprehensive Movement Disorders Center. She began, very appropriately, by explaining the causes of Parkinson's Disease (PD). Exogenous toxins, genetic susceptibility, and consistent loss of the neurotransmitter dopamine are considered the current suspects.

Dr. Stewart then explained the various medicinal treatments currently available for PD. She began with the drugs amantadine and selegline. The former blocks excitotoxicity, which is caused by the above-mentioned toxins, while the latter works to increase the amount of dopamine in the brain. Next in line were dopamine agonists along with carbidopa and levodopa. These drugs were recommended by Dr. Stewart as "long-acting medications," and she remarked that carbidopa/levodopa, along with comtan, were the most efficacious medical treatments for PD.

Then, Dr. Stewart reached the final topic of her presentation, a discussion of deep brain stimulation (DBS), which is a surgical procedure currently used to treat PD. Although it is a relatively new type of treatment, Deep Brain Stimulation offers PD patients new hope in overcoming the suffering often associated with the illness. According to Dr. Stewart, DBS lowers the abnormally high firing rates of neurons that accompany PD, diminishing and, in some cases, totally eliminating symptoms such as tremors.

Dr. Stewart's finale was truly powerful. It consisted of several videos showing patients that had undergone DBS. The results, as represented in the videos, were very impressive. Before the operation, patients exhibited stiff motion, took small steps, had to pivot to turn, and were literally plagued by tremors. Afterwards, the patients'

(continued on page 7)



Rex Denton and his caregiver Glo Denton

“Spousal caregivers often described the most significant challenges as watching their partner struggle and be frustrated.”



Anne Coon and her caregiver Robert Coon

Caregivers: Approaching Parkinson's

Much of the long-term care of Parkinson's patients are provided by friends and relatives, but are primarily provided by spouses. Since caregiving is a physically and emotionally exhausting experience and way of life, finding ways to approach and cope with difficulties is crucial. Much of the information provided here are obtained from interviews with caregivers and patients.

Role of Caregiver

Caregivers provide both physical and moral support to the patient. As the disease progresses, Parkinson's patients lose the ability to perform regular physical tasks of daily living. The caregiver serves as the patient's "muscle," helping the patient walk, get in and out of bed, and perform household chores. Caregivers also provide moral support by encouraging the patient to be independent, lifting the patient's spirits with compliments and expressions of love, and attending support groups so they both can learn more about the disease together and socialize with those who share the same concerns.

Caregiver Burdens

Caregivers often experience stress and fatigue because they must provide care for the patient and perform numerous household duties. As the disease progresses, the burden on caregivers increases significantly, resulting in more tasks and greater time commitment. As symptoms become more severe, caregivers must assume new responsibilities.

Apart from physical strains, caregivers also experience emotional stresses, such as feelings of guilt for not providing enough care, feelings of uncertainty in the progression of the disease, adjustments in family roles and activities, and changes in the psychology of the patient.

Greatest Challenges Faced by Caregivers

Spousal caregivers often described the most significant challenges as watching their partner struggle and be frustrated. When asked what affect does watching his partner's frustrations have on him, caregiver Harold Driggers from Fremont, CA responded, "It's half-way killing me." It is often very difficult on the part of the caregiver who has to witness the slow decline of a loved one.

Rewards of Caregiving

Although caregiving may be burdensome, it is a rewarding experience. The patient and the caregiver get closer in their relationship because they spend more time together and learn to understand each other's concerns and needs better. The greatest satisfaction for a caregiver helping and comforting a loved one..

What hasn't changed in life?

Some spouses see their support as a further development of their relationships rather than on obstacle. They accept that their relationship and roles are constantly evolving along with the progression of the disease.



Former caregiver Marge Rogers

Caregiving Facts

? Men have a higher incidence of Parkinson's disease, which would influence the gender of the caregivers to be predominantly female.

? Studies show that women caregivers, primarily wives and daughters, experience a higher rate of depression than men.

? According to the FCA (Family Caregiver Alliance), Parkinson's caregivers provide 96 hours of care per week on average.

? Parkinson's caregivers are older and have spent more time caring compared to those of other brain impairments.

? In various surveys, a high percentage of PD caregivers have expressed the need for respite or emotional support.

ASK THE DOCTOR: A CONVERSATION WITH DR. CLIFFORD SHULTS, PROFESSOR OF NEUROSCIENCES, SCHOOL OF MEDICINE AT UCSD AND PRINCIPAL INVESTIGATOR OF THE STUDY ON COENZYME Q10

We know and understand that PD families everywhere are continually searching for information about new products and research studies that show promise to help delay the progression of the disease or to offer a better quality of life to the patient.

Dr. Shults, it is our understanding that the multi-center study that you, Dr. Richard Haas and the study group recently completed has been described as a Phase II study that was designed to examine the safety and tolerability of several dosage levels of coenzyme Q10. Also, your work has been called one of the most promising programs in Parkinson's research. There are, however, important questions yet to be answered such as dosage, whether the beneficial effect is primarily in early Parkinson's victims as opposed to individuals who have had Parkinson's for a long period, and of course, longer-term safety and side effects.

? Dr. Shults, can you briefly explain what is coenzyme Q10 and how it works to help Parkinson patients?

Coenzyme Q10 is a constituent of the mitochondria, a part of the cell that produces energy. It has been determined that Parkinson patients have reduced coenzyme Q10 levels. When the subjects were given high doses of coenzyme Q10, the study showed an improvement in mitochondrial function.

? Since the release of your research article we have had numerous calls and emails from patients asking if they should go out and buy coenzyme Q10 from their local pharmacies or from Vitaline Formula. What advice would you give them?

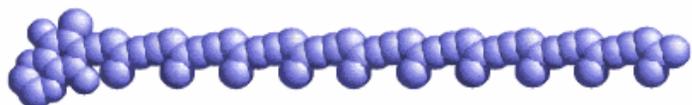
Our study was designed to determine whether there was evidence that treatment with coenzyme Q10 could slow the progression of Parkinson's disease, but the study did not have any patients to prove definitively that it could slow the progression of the disease. Studies, such as ours, are carried out to determine whether a treatment is promising enough to justify investment of the time, effort and money to carry out a large definitive study. The results of our study were very promising, but it would be premature to recommend to patients to begin to take high doses of coenzyme Q10 until a large, definitive trial has been completed.

? What are the possible side effects, if any,



Clifford Shults, M.D.
Professor of
Neurosciences
UCSD

"The results of our study were very promising, but it would be premature to recommend to patients to begin to take high doses of coenzyme Q10 until a large, definitive trial has been completed."



3-D Structure of CoQ10



Comedy Corner

"Doctor, doctor, will I be able to play the violin after the operation?"
 "Yes, of course..."
 "Great! I never could before!"

"We have no data to suggest its effectiveness in the later stages of PD."



Comedy Corner

Things You Don't Want to Hear During Surgery:

- Oops!
- Has anyone seen my watch?
- Damn! Page 47 of the manual is missing!
- Well this book doesn't say that... What edition is your manual?
- Wait a minute, if this is his spleen, then what's that?
- If I can just remember how they did this on ER last week.

ASK THE DOCTOR

from taking coenzyme Q10?

The drug was well tolerated in our study. However, there are reports in the medical literature that it may interfere with Coumadin's action in those patients taking Coumadin.

? Is there any indication that coenzyme Q10 will be effective in those in the later stages of Parkinson's?

We have no data to suggest its effectiveness in the later stages of PD. The early-stage subjects were studied because it is easier to follow disease progression in patients before they are on the standard medications for Parkinson's disease, such as levodopa or dopaminergic agonists.

? Does coenzyme Q10 interfere or have any effect on other medications such as one of the dopamine agonists or levodopa?

Our study only looked at patients before they began on such medications. In an earlier, small study conducted at UCSD we found no effect on standard medications used for Parkinson's disease

? If a patient decides to take either the over-the-counter version of the medication or purchase it from Vitaline Formula, is there a need to consult his neurologist?

I would recommend that before taking any over-the-counter medications, one should always discuss it with your physician.

? Is there any evidence indicating that the synthetic version of coenzyme Q10 will or will not work as well as the natural version?

There have been no clinical trials that have examined this issue.

? Why were the participants of the study

Open Doors

And now these three remain: faith, hope and love. But the greatest of these is love.

I Corinthians

13:13

Mitch Lechelt was diagnosed with Parkinson's disease in 1995 at the age of 37 while he was working as an American Airlines pilot. As a songwriter and musician, he believed that God had given him the talent and passion for music so that he could reach out and touch the lives of everyone affected by PD. He wrote the title track, "Open Doors," to a compilation CD, which revolves around the themes of faith, hope, and love, and includes songs donated by eleven Texas songwriters. All proceeds from the sale of CDs go directly to Parkinson's research. The Open Doors CD has raised over \$5000 and is recently being sold internationally. The CDs are available for \$13 each and can be purchased through the APDA Information & Referral Center, Presbyterian Hospital of Dallas, 8200 Walnut Hill Lane, Jackson Building, Ground Floor, Dallas, TX 75231.

For more information, go to www.opendoorscd.org or contact Jessica Vazquez at (214) 345-5031.



Comedy Corner

"The doctor said he would have me on my feet in two weeks."
 "And did he?"
 "Yes, I had to sell the car to pay the bill."

"Currently we are enrolling patients in a pilot study at UCSD."

ASK THE DOCTOR

given Vitamin E? Isn't that also an anti-oxidant?

There is some evidence from biochemical studies that addition of vitamin E increases the antioxidant effect of coenzyme Q10. All the subjects received 300mg of Vitamin E, four times per day.

? Do you plan further research on coenzyme Q10? If so, how would the new study be different from what you have already done?

Currently we are enrolling patients in a pilot study at UCSD. It is designed to look at the safety and tolerability of doses between 1,200 and 3,000 mg. We will be enrolling about 25 patients. We are also working on another new multi-center study design that would enroll approximately 400 subjects. The larger study likely could not begin for at least a year.

? If a person is on an agonist and not taking levodopa, can they participate in the next phase of the study?

Yes, in the small study at UCSD.

The Man Behind the Discovery of Parkinson's

"Why dost thou quiver man?"
 "The palsy and not fear provokes me."
 — Shakespeare, *Henry VI*

As early as 1590, a neurological disease with tremors as symptoms was widely known, appearing in all types of writing, even Shakespearean plays, as shown above. However, it was not until 1817 that this disease was officially described and named. The man behind the discovery was James Parkinson, a British physician. He had made numerous observations of patients suffering from tremors, so he decided to describe the disease that caused them. He referred to the disease as *paralysis agitans*, which means "shaking palsy." His sixty-six page essay established the shaking palsy as a clinical entity, and, to this day, it remains a source of useful information about Parkinson's disease. Because Parkinson provided the first accurate description of the disorder in his *Essay on the Shaking Palsy*, the disease has become widely known as Parkinson's disease.

For more information, visit www.macalester.edu/~psych/whathap/UBNRP/parkinsons/history.

? How many years is it likely to take to come to definitive results on whether coenzyme Q10 is truly going to be a useful and safe approach to neuroprotection of dopamine producing cells and the slowing of PD's progression?

Likely 5 to 7 years before we have definitive results on whether coenzyme Q10 will be useful to neuroprotection of dopamine producing cells and the slowing of the PD's production.

? The initial results of your work indicate that coenzyme Q10 works by improving the functioning of existing cell mitochondria. Do properly functioning cell mitochondria increase the efficiency of dopamine production or does it even prevent cell death?

Coenzyme Q10 probably doesn't affect the production of dopamine, but it does help to protect the cell from injury.

? Are other promising drugs or proteins in the research process that show as much promise as coenzyme Q10 for neuroprotection to dopamine neurons?



Comedy Corner

**More Things
You Don't Want to
Hear During Surgery:**

- Damn, there go the lights again...
- Everybody stand back! I lost my contact lens!
- Could you stop that thing from beating; it's throwing my concentration off.
- I wish I hadn't forgotten my glasses.
- Steril, shcmeril. The floor's clean, right?
- Let's hurry, I don't want to miss "Bay Watch"

"The study reinforces the conviction that mitochondrial dysfunction plays a role in PD."



Comedy Corner

The seven-year old girl told her mom, "A boy in my class asked me to play doctor." "Oh, dear," the mother nervously sighed. "What happened, honey?" "Nothing, he made me wait 45 minutes and then double-billed the insurance company."

Inside Story Headline

Not that I am aware of any compounds that have been studied as far as coenzyme Q10, but there are other promising compounds that need to be studied.

? Has your research given you any more information on the cause of Parkinson's disease and how coenzyme Q10 fits into the big picture?

The study reinforces the conviction that mitochondrial dysfunction plays a role in PD.

? Have you developed any greater insights during your research on genetics and Parkinson's disease?

There is the PROGNI study, which is making headway in this area. In this study we are enrolling siblings, brothers and sisters, who both have PD. (if you want information on this study, call 858-273-6763)

? Are there any new insights into what neurotoxins actually trigger expression or activation of Parkinson's genes and cause dopamine cells to start dying at an accelerated rate?

There is some interesting work being done that is looking at Paraquat, an agricultural pesticide.

? In looking at the big picture of Parkinson's research, what do you feel are the most promising lines of investigation? For example, new medications or drugs, gene therapy, stem cells, and surgical procedures all show promise. Which may be the silver bullet?

Neuroprotection, at least for the short-term.

? One of the articles published by a national Parkinson organization mentioned that the Huntington Study Group did not recommend coenzyme Q10 as a treatment for Huntington's disease. Can you explain why?

The results of the study group, which was a larger group, were inconclusive, although there was a slight trend toward benefit.

Finally, we would like to express our sincere appreciation for this opportunity to interview you (Dr. Shults) regarding this exciting study and look forward to more exciting and promising news in the months and years ahead.

Symposium (continued from page 1)

movements became calmer and much more natural, and the tremors had virtually disappeared. The operations for the three patients shown appeared successful, but as the following speaker would mention, DBS does involve certain risks.

Heit's Remarks:

Then, the Parkinson's symposium proudly welcomed the next speaker: Dr. Gary Heit, MD, PhD. Dr. Heit, who has personally performed numerous DBS operations, discussed procedure involved in DBS. Fortunately, he was able to break it down into two very simple questions. "How do you find the spot where the electrode goes, and how do you get to the spot?"

According to Dr. Heit, the "spot" is the sensorimotor region of the brain, which is a small subsection of the subthalamic nucleus. MRI scans are common methods to locate this spot, but even they are not perfect due to inherent distortion. The question of reaching the spot can be answered with two words: stereotactic frames. For those readers without MD's, stereotactic framing is a lengthy procedure used to place the electrode in the proper location. Although the procedure requires a great deal of attention to detail, it ensures very high accuracy in placement.

Having taught everyone the intricacies of DBS, Dr. Heit decided to cover the risks. Apparently, complications related to DBS range from 8% to 27% of all cases, with serious complications occurring in less than 2%. On a positive note, Dr. Heit did mention that the Stanford Medical Center has an 8% complication rate, placing it among the most successful hospitals in the country.

McGuire's Remarks:

The final speaker, Kay McGuire, RN, BSN, discussed the basic preparations for and the after effects of DBS. Her main point was clear: "We want to make sure we will help you, not hurt you." Therefore, she emphasized the necessity to follow all rules before and after the operation. Toward the end of her discussion, she welcomed a panel of three patients who had successfully undergone DBS. The panel then fielded a multitude of questions from the audience. How did you feel after the operation? Do you regret doing it? What improvements resulted from DBS? These were accompanied by many others. The audience was certainly curious about the procedure, but they clearly showed that they wanted to be well informed before they made any decisions.

The cost of DBS ranges from \$100,000 to \$120,000 for the hospital, and, according to Dr. Heit, that translates into about \$4,000 for patient expenses after insurance deductions. The Stanford Medical Center has offered DBS since 1998, and 150 DBS procedures have been performed there. For more information about the Stanford Medical Center, visit <http://www.stanfordhospital.com/>. For specific information regarding PD treatment and resources for patients, visit <http://parkinsons.stanford.edu/>. Finally, to find out more about deep brain stimulation, email the Stanford Medical Center at smdc@medcenter.stanford.edu or call Melanie Vancil at 650-723-2116.

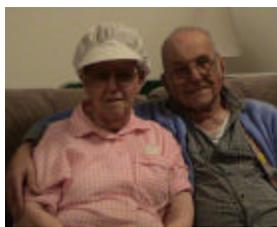
Caregiving (continued from page 2)

Family Care vs. Nursing Care

Caregivers sometimes consider placing the patient in a care facility when caregiving becomes too burdensome or when it becomes detrimental to the caregivers' health. However, nursing care cannot match the top-quality personalized care provided by family members who know the patient's needs. There are alternatives to nursing care that can help to ease the burden. Caregiving can be distributed among family members. Caregivers can also hire substitutes during times of over-exertion.



Jody Driggers, her caregiver Harold Driggers, and their son



Charles Kohl and his caregiver Ila Kohl

Coping Strategies and Suggestions

Patience is the key. Caregiver Glo Denton said, "Caregiving is the hardest thing I've ever done." She copes with caregiving by taking it one day at a time and sometimes one hour at a time.

Seeing challenges they experienced as secondary to what the patient was experiencing.

Encouraging the patient to stay active and involved.

Get sufficient sleep and maintain good diet and exercise.

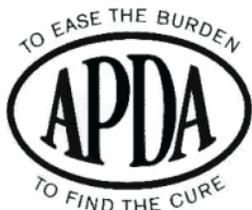
Share experiences with other caregivers through support groups. Support groups are one of the most effective ways to cope with the burdens of caregiving. Through support groups, caregivers and patients develop new friendships and share their experiences with those who understand their situation.

Sources for Discounted Medications:

- AARP (800)456-2277
www.aarppharmacy.com
- Canadameds
(877)542-3330
www.canadameds.com
- Costco
www.costco.com
- Medicine Assist Program
(866)633-7482
www.unitedhealthalliance.com
- People's Prescription Plan
(800)566-0003
www.peoplesrxcard.com
- Prescription Solutions
www.rxsolution.com
- Rx Hope (908)850-8004
www.rxhope.com

Disclaimer

This document is published to promote greater awareness of the problems caused by Parkinson's disease. Neither the Parkinson's News Network, 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.



Local Support Groups

Berkeley:

3rd Mon., 10am-12pm
N. Berkeley Sr. Ctr.
Call Mitz for details 510-527-9075

Daly City:

1st Tues. 3:00-4:00 pm
Doelger Sr. Center
101 Lake Merced Blvd.
Leonard Ke 415-587-1285

Fremont:

4th Mon., 7:00 p.m.
Fremont Sr. Ctr.
40086 Paseo Padre Pkwy.
Lettie Webb 510-656-6393 or
Bob Coon 510-794-7988

Hollister:

1st Tues, 1:30-3:30
1st Presbyterian Ch.
2066 Cienega Rd.
John Skinner 831-637-6755 or
Shirley Kennedy 831-637-3839

Los Altos:

3rd Tues., 1:30-3:30
Foothills Congregational Ch.
461 Orange Ave.
Diana Preice 408-739-5207

Magnolia/ 2nd Thurs., 1:30-3:00

The Magnolia of Millbrae
Peninsula
201 Chadbourne Ave.
Leon Rosenthal, 650-348-3480

Marin Cty: 4th Tues., 2 - 4

Redwoods, Mill Valley
Gloria Rashti 415-381-6680 or
George Raddue 415-488-9137

Monterey:

3rd Mon., 2:30-4:00 Hayes School
200 Coe Ave. Seaside
Helen Garrett 831-657-4241 or
Kathy Warthan 831-372-7510
Mt. Diablo Parkinson's Network: 2nd Mon.,
12:30-2:30, Grace Ch, 2100 Tice Valley Blvd,
Walnut Creek, Cliff Terry 925-673-0708.

Early Stage: 3rd Sat., 10-12, Grace Ch. 2100
Tice Valley Blvd, Walnut Creek, Nancy Wahl
510-236,7065, Philip Wheeler 510-527-3588

Pleasanton Valley: 2nd Sat. 10:00-noon,
Senior Center, Pleasanton, Evelyn Williams,
925-846-5824 or Cliff Terry, 925-673-0708

Caregivers Walnut Creek: Last Wed.,
for time and place, call Jewel Wallach 925-
256-0312

Oakland: 1st Thurs 1:30-3:30

2757 Telegraph Ave
Leslie Bennett, 510-835-2131 X104
Robert Lemon 510-526-2078

Palo Alto: 2nd Wed., 2-3:30

Avenidas (Sr. Cent.)
450 Bryant St., PA
Ellen Dietrich 650-327-2811 or
Sridevi Sheshadri 866-250-2414

Redwood City:

3rd Fri., 12:30-2:00
Sequoia Health & Wellness Ctr.
702 Marshall St.
650-367-5998

Salinas: 4th Wed. 2:00-3:30

Salinas Adult School
20 Sherwood Pl.
Kendra Webster, Delmar Research, 831-
424-4359

San Francisco: 3rd Tues. 2-4pm

Christ Church Lutheran
1090 Quintara St. (at 20th)
Julie Hevezi, 415-476-9276

San Jose: 1st Fri., 10:00-noon.

St. Francis' Ch.
1205 Pine Ave.
Betty Havens 408-269-2167

San Jose Caregivers: 4th Wed. 1-3

St. Francis Ch.
1205 Pine Ave
San Jose

Linda Filice 408-978-2859

San Mateo Caregivers: 1st Wed. 2-3:30

Mills Health Ctr., Ellsworth Rm.
100 San Mateo Dr.
Carol Hoffman 800-654-9966

Santa Cruz: 1st Wed. 12:30-2:30

St. Stephen's Lutheran Ch.
2500 Soquel Ave.
Layne Carey 831-461-0757

Saratoga: 3rd Tues. 2:00-4:00

Lois McPherson 408-867-1807

Sonoma County: 1st Sat, 1-3
YMCA

1111 College Ave, Santa Rosa
Davis Brown 707-538-4952

Sunnyvale: 2nd Wed 1:00-3:00

1st United Methodist Ch.
535 Old San Francisco Rd.
Linda Filice 408-978-2859

Turlock: 1st Thurs. 2:00-3:00

Emanuel Hospital
Delbon St.
Marion Johnson 209-634-3157 or
Jean Okuye 209-394-2421

Walnut Creek Caregivers:

Call for time and place 925-256-0312

YPSG: 2nd Sat. 10:00-noon.

YWCA Palo Alto 4161 Alma St. Palo Alto
Rich Brongel 650-952-3849 or
Judy Trivedi 408-735-7038