

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

*Fall Quarterly 2006*

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## **Surgical Issues Relating to Parkinson's Surgery**

*By Conrad T.E. Pappas, M.D., Ph.D  
Functional and Stereotactic Neurosurgeon  
Director, Clinical Functional Neuroscience Program,  
The Permanente Medical Group, Inc.*

When Parkinson's patients contemplate having surgery, they and their families need to be well informed before surgery is undertaken. Many concerns come up that are part of the overall surgical experience. All parties involved hope that the patient will improve with surgery - STN DBS, GPI DBS, or with pallidotomy. But, with surgery, there are expected risks with complications. These complications include hemorrhages, infections, medical problems, wires breaking, mal-positioning of the electrode and any type of neural deficits. These complications may occur immediately or later after surgery. Besides surgical complications, other patient concerns occur. Examples of these are the patient will have a unique experience in the operating room while being awake, having a "new body" that "works better" because of fewer tremors, different body images due to wires, burr hole caps and batteries, etc. And, just as important for the family, with the new physical changes that occur, the support before, during and after surgery will be different.

It cannot be stressed enough that talking to the surgical team is essential. Bring questions, read literature and talk to family members, and if possible past patients. Remember, the surgery does not cure the disease. Therefore, the disease will progress; there can be further cognitive decline, non-motor decline like bladder dysfunction, or cardiac dysfunction or decline in motor function. Remember, some Parkinson symptoms, like balance and speech problems, usually do not improve. Therefore, have realistic expectations. Again, surgery is not a cure. Overall, most patients

and their families will be delighted with the improvement.

Patients need to be informed what will happen. This helps decrease anxiety tremendously. First, the placement of the head frame. Needle injections and placement of the pins does have discomfort involved. Once the frame is placed, the patient should expect significant pressure from the frame, which after a short period, will greatly decrease. Patients should relax and take slow deep breaths to help deal with this part. Patients with frameless procedures will experience small incisions and placement of screws after having been given local anesthesia and some form of intravenous or by mouth relaxing agents.

Then the MRI and/or CT scan will occur. Timing depends on the surgical team. Patients with claustrophobia will be given intravenous or by mouth relaxants to help them.

The surgical experience in the operating room needs to be well described before surgery. The patient is awake and will have a unique experience that can be frightening, overwhelming and confusing. Patients need to know that several medical staff personnel will be in the room helping the patient, talking about equipment, recordings, etc. and staff members coming and going. We help the patients by talking to them, asking how they are doing and making sure they are comfortable. The surgeon should inform the patient what the next step will be so the patient will not have any surprises, particularly with the burr hole. Drilling the burr hole creates noise and vibration and but is painless for the patient and usually lasts less than a minute.

Patients need to inform the team how they are doing. If salivation is a problem, the patient needs to be suctioned quickly. Otherwise the case might have to be aborted due to respiratory distress. Pillows, egg

crate, massage, coaching can all help make a successful case. Patients need to be informed that the case will be aborted if bleeding occurs, anxiety or fear become overwhelming, rigidity interferes with breathing, severe hypertension occurs or other medical problems manifest themselves. We tell our patients and their families that even though the patient/family is disappointed, there is, in most situations, another day in the future to try again. Usually this try will succeed.

While testing the DBS thresholds, the patient needs to be aware enough of any double vision, unusual sensory and motor changes to help the team with placement. Also, the patient needs to expect medical personnel to move his/her limbs to check for electrode recording changes.

After the DBS is placed and the wound is closed, the placement of the wires and battery are done. Sometimes this is done the same day or later. After the procedure, which is done under general anesthesia, the patient will find himself/herself in the recovery room. We find that Parkinson's patients take longer to wake up than non-Parkinson's patients. It is important to start the Parkinson's medications as soon as possible to help relieve rigidity, stop disorientation and tremor. Patients feel much better when their medications are started soon after surgery. Surgical complications are unfortunately expected in any series of patients undergoing motor disorder surgery. Intracerebral hemorrhages are the most worrisome. These hemorrhages can cause death (rarely) but usually a neurological deficit such as weakness either temporarily or permanently can occur. With the best standard of care, this problem can occur. It is unavoidable since the surgeon, even with the excellent imagery capabilities we have, cannot miss small blood vessels as the recording electrode, or DBS, passes through the brain. Sometimes it occurs immediately or it can be delayed. If it does occur, it usually occurs during the first day almost minutes to a few hours after the start of the case. Of course, the surgery is stopped and a CT scan is obtained. Further treatment after that varies tremendously depending on the area and size of the bleed and clinical picture. Another unavoidable problem is infections. From wound infections to cerebral abscesses and meningitis, this problem will occur at any medical center. Patients are given pre and post-surgical antibiotics but some cases still get infections. *It is imperative that patients keep their wounds clean and dry and inspect them daily.* At the sign of any pus, tenderness, redness, the patient needs to come in for an examination. Sometimes, the DBS electrode can be saved before the

infection spreads too widely. **Family is the key** – they can help the patient check the wounds. Seizures can be a warning that a bleed has occurred. It also can occur without any bleeding. There is a small risk of seizures during surgery due to electrode penetration. If seizures occur, the case is aborted. In all situations, when a seizure occurs a CT scan is obtained to rule out hemorrhage, edema and other acute problems. Seizures can occur intra-operatively or post-operatively.

Behavior, mood and judgment, etc. can change after surgery. **Family must be aware of these changes.** Behavior changes can be: increased hyper-sexuality, increased monetary spending, disorientation, depression and mania. Families should not permit the patient to make any major decision for about a month after the surgery. This concept should be told to the patient and the family pre-operatively. This can lead to deterioration in marital and family relations. Even though motor improvements occur, the behavioral and judgment changes can cause disturbances in family and social interactions. Counseling should be offered. Counseling might also be needed when patients have significant improvements without any behavioral changes and want to be more independent. Family members who are used to treating the patient might not realize that their attention, once needed, is no longer appreciated nor wanted since the patient can handle the situation alone.

When the stimulator is programmed, the patient must be aware of unexpected neurological sequela. Double vision, hot flashes, involuntary motor function, tingling, depression, mood swings, etc. can occur. This might be immediate or delayed. The patient should not despair but see the neurologist for further programming. Remember, the neurologist has four contacts and changes in voltage, rate, and pulse width to help decrease or eliminate unwanted side effects.

Patients also must be aware that external forces can cause havoc with DBS. Examples are power tools, electric shavers, electric toothbrushes, microwaves, antitheft devices and metal detectors. Some external factors can be deadly. Be aware of MRI's, pulse-modulated radiofrequency diathermy and power stations, as examples. MRI's should be performed only at centers that are involved with the DBS MRI protocols.

Patients and family should be optimistic about Parkinson surgery. DBS and pallidotomy are proven surgical techniques with good outcomes. But, patients and family need extensive, pre-operative training to help with the many faces of the surgery and the

complications to achieve a smoother post-operative course.

*We would like to send a special thank-you to Dr. Pappas, for taking time out of his very busy schedule to write this article for the PPSG newsletters. The outstanding staff of the Functional and Stereotactic Program in Sacramento, CA, graciously assist, educate, and support patients/family members before, during, and after the DBS surgeries. The surgeries are performed weekly and have helped many patients/families improving the quality of their lives.*

## **Brain Surgery Found to Help Parkinson's Patients**

Study Yields Encouraging Results to Alleviate Some Symptoms of Disease

*By Siri Nilsson, BBC News*

**Aug. 30, 2006** — - Brain surgery might make the ordeal of Parkinson's disease a little easier for some patients, according to a study published in this week's issue of the New England Journal of Medicine.

While several medications can help control the symptoms of this degenerative disease, they can produce side effects, including uncontrollable body movements that can be almost as disturbing as the shaking and tremors of the disease itself.

Parkinson's affects 1.5 million Americans. It can take away a person's ability to move by causing tremors, stiffness, shuffled walk, muffled speech. The new study confirms that a surgery to provide deep-brain stimulation, or DBS, might help when medications have failed.

"For patients and their families, this is a landmark study because it focuses on what is really important to them: quality of life. And it shows, very clearly, that DBS improves quality of life," said Dr. Jaimie Henderson, director of stereotactic and functional neurosurgery at Stanford University Medical Center.

The study followed 156 patients with severe Parkinson's disease, all under the age of 75. Half of the patients took medications to manage their disease, while the others received DBS.

During the procedure, a battery-operated neurostimulator is surgically implanted into the brain. That stimulator can improve motor symptoms in some Parkinson's patients by blocking the abnormal nerve signals that cause tremors and other symptoms. According to the study, patients treated with this surgery had better mobility, quality of life and emotional well-being than the patients who received standard medications.

## **Promising Results, Yet Caution Advised**

Most doctors already know that deep-brain stimulation helps Parkinson's patients, but this study is the first to prove that the surgery brings greater overall benefits. "This may be the first published article to demonstrate ... that surgery is better than the best medical therapy," said Dr. Gordon Baltuch, director of the Center for Functional and Restorative Neurosurgery at the University of Pennsylvania.

The study is also important because it shows that DBS can help make life better for those with Parkinson's, given how patients feel after the surgery. Some doctors suggest this study will have an impact on the treatment of patients, as the surgery might become more widely used.

Dr. Daniel Tarsy, director of the Parkinson's Disease and Movement Disorders Center at Boston's Beth Israel Deaconess Medical Center, said, "At present, DBS is often regarded as somewhat of a last-ditch effort to improve function in patients with advanced PD. ... The findings of this study should lead to greater use of surgery for treatment of this group of patients." "Hopefully, this study will provide enough evidence to convince these physicians of what functional neurosurgeons have known for years: DBS is the best treatment for Parkinson's disease when medicine begins to fail," Henderson said.

The surgery is not fail-safe. While medications generally bring more side effects than the surgery, serious side effects were more common among patients who received the neurostimulator. One study patient actually died during the brain surgery.

One doctor voiced concern about the enthusiasm this study might generate. "It is important to stress that DBS is not a cure," said Dr. William J. Weiner, director of the Maryland Parkinson's Disease and Movement Disorders Center. He said the study also does not help doctors understand if the surgery is best for patients early in their diagnosis, or for those with more advanced cases of the disease. "This study will not help us decide this issue, and there may be an over reaction to the results of the study," Weiner said. "It may also push patients and neurologists into performing DBS before it is required."

Brain surgery might not be the best option for all patients. But for some, this neurostimulator could be life changing.

*//abcnews.go.com/WNT/Health/story?id=2375813&page=1 . This article was forwarded by James McKarns, of San Mateo, California. Thanks, Jim!*

## How to Talk to Your Doctor

People are often anxious and apprehensive when they visit their physicians. This can be caused by having a new medical problem, feeling that the visit is too rushed, inability to understand the medical terms used, or coping with multiple diagnosis, procedures or medications.

The key to having a successful relationship with your doctor is good communication. Here are some tips to help you develop and maintain a productive partnership:

### Be Prepared

Have your questions written down and use this as a checklist and guide when speaking to your doctor. Be concise. When describing physical complaints, be as specific as possible.

### Questions to ask regarding diagnosis

✍️ What is the problem? Could it be something else?

✍️ What caused this? How can it be prevented in the future?

✍️ What is the typical course and outcome?

✍️ Is it contagious? Any special precautions or signs to look for?

✍️

### Questions to ask regarding treatment

✍️ What are the treatment options?

✍️ What are the risks, benefits and costs of each?

✍️ What if I choose to do nothing at this time?

✍️ What are the non-medical options (diet, exercise)?

### Questions to ask regarding diagnostic tests ordered

✍️ What do you expect to learn from the tests?

✍️ How much will these tests cost? Are they covered by my insurance?

✍️ What preparation should I make (fasting, medications, etc.)?

✍️ What are the possible side effects?

✍️ Please explain in plain language what the test results mean.

### Questions to ask if medications are prescribed

✍️ What is the name of the drug, and what does it do?

✍️ How and when do I take it, and for how long?

✍️ What food, drinks, medication or activities should I avoid while taking this drug?

✍️ Are there any side effects and what should I do if they occur?

✍️ Can you provide any written information about the drug?

### Other suggestions

✍️ You may wish to take notes or bring someone with you. A friend or relative can help remember your questions and the physician's answers.

✍️ You might also ask for your physician's permission to tape-record your session.

✍️ Sometimes it can be useful to record doctors' visits, especially when you are seeing several physicians. This can help you and your doctor track all the medical care you are receiving.

✍️ Be sure to discuss your specific desires regarding the medical care you want in the event you are unable to make decisions for yourself (e.g. you are comatose, unable to speak, etc.) Ask your doctor for a Durable Power of Attorney for a Health Care form or call Senior Focus at 800.654.9966 to request one.

✍️ Doctors are very busy. If you want or need a longer appointment time, be sure to say so when you are scheduling it.

✍️ Remember that your doctor is only human. Make an effort to communicate clearly your problems and concerns, rather than expecting him or her to know what they are.

✍️ Be realistic about what your physician can do for you, and most importantly, be an active participant in your health care. This partnership will work best if you understand and carry out your rights and responsibilities.

*The above information was forwarded by Martha Gardner. Martha is a PPSG board member, as well as the APDA (American Parkinson Disease Association) Information and Referral Center at Stanford, California. Thanks, Martha!*

To learn more about DBS surgeries, read "Deep Brain Stimulation for Parkinson's Disease" booklet by Parkinson's Disease Foundation( 800.457.6676; [info@pdg.org](mailto:info@pdg.org); [www.pdg.org](http://www.pdg.org)), and "Your Activa<sup>®</sup> Therapy, Patient Manual" by Medtronic(800.551.5544; [www.medtronic.com](http://www.medtronic.com)). Family members or caregivers reading the Medtronic patient manual can assist the patient living with Activa<sup>®</sup> Therapy. **If the stimulator has been placed, always tell any medical personnel that the patient has an implanted brain stimulator and tell them where it is located.** If medical personnel have any questions, they should contact Medtronic at 800.510.6735.

**Visit the PPSG website to learn about upcoming events, what's going on with the PD research, and many helpful ideas:**

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

## November 2006 Elections – Key to Our Cure? Why We Need Help

*By Bill Franklin, an advocate for Parkinson's research*

The November 2006 elections are only weeks away. We have an opportunity to increase the political support for stem cell research that has the potential to cure Parkinson's, Alzheimer's, Diabetes, Cancer, Multiple Sclerosis, Spinal Cord injuries and many other debilitating conditions.

While we here in the United States continue to create barriers to stem cell research through legislation, court challenges, and the lack of Federal government funding, other countries like Singapore are expanding their research efforts by hiring some of our brightest researchers, providing companies incentives to relocate, and are overall aggressively supporting stem cell research.

We still have a chance to take a leadership role in this new technology if we elect those who support stem cell research.

Those of you who have a disability cannot count on your advocacy organization to take care of this for you since many such as PAN are 501© (3) non-profit organizations and cannot take a stand on political candidates. We need to do it ourselves.

By a wide margin, the majority of the US population, medical researchers, the US House, and the US Senate support embryonic stem cell research. Unfortunately there were not enough votes in the House to override a Presidential Veto on legislation that would have moved the research forward in the United States.

It is time that we elect candidates that support us in our fight for cures. Many researchers believe that stem cell research could play an important part in the development of cures or improved therapies... What we need to do is ...

- ~~///~~ Commit to taking an active role in our future
- ~~///~~ Actively support stem cell research
- ~~///~~ Find out where those running for office in November stand on stem cell research
- ~~///~~ Support the candidates that are most committed to stem cell research – join these candidate's campaign team
- ~~///~~ Continue to track web sites that report candidates' positions on stem cell research
  - o Stem Cell Action Network (SCAN) - <http://stemcellaction.org/> - has a Stem Cell Voter

Score Card – lists candidates and their stem cell research positions <<still being updated>>

- o The Coalition for the Advancement of Medical Research (CAMR) - <http://www.camradvocacy.org/> - <<told they would have candidate positions also in the future >>

~~///~~ Make sure that the campaign and the candidate are aware of the support they received from stem cell advocates.

I hope that every advocate would join me in declaring...

"I WILL VOTE IN NOVEMBER BUT I WILL NOT VOTE FOR ANY CANDIDATE WHO DOES NOT SUPPORT EMBRYONIC STEM CELL RESEARCH."

LET THEM KNOW THAT IF THEY WANT YOUR VOTE THEY MUST SUPPORT THE RESEARCH.

I would like to suggest that for many diseases / disorders the best use of time allocated to advocacy during the next 9 weeks should be to help elect pro-stem cell research candidates. In past elections, many advocates would share their preferences quietly and then spend the next 2-6 years trying to convince those elected to support their causes. Why not elect supporters in the first place?

Now, let's get going and make it happen. We can be in control of our future.

**STEP 1 – MARK YOUR CALENDAR TO VOTE – NOVEMBER 7, (TUESDAY)**

2006

**STEP 2 – CHECK THE WEB SITES FOR THE CANDIDATES LATEST POSITIONS ON STEM CELL RESEARCH**

**STEP 3 – GET AT LEAST 5 ADDITIONAL VOTERS COMMITTED TO ELECTING CANDIDATES WHO SUPPORT STEM CELL RESEARCH**

**STEP 4 – VOTE (either absentee or in person on November 7)**

**STEP 5 – REMIND OTHER SUPPORTERS TO VOTE**

Don't assume that your family and friends know how important this issue is to you or assume that somebody else will contact them

We can win, but each of us needs to take action. Let's start *NOW*. Save this article as a reminder and start educating your friends and family on the value of the research - one person at a time.

## Notes Taken By Robin Riddle From the 9/14 PPSG Volunteers Luncheon:

Fellow group members Le, Solna, Linda and I attended a PPSG (Parkinson's Patients Support Groups, Inc.) Volunteers luncheon on Thursday, September 14. Dr. Melanie Brandabur, the Clinical Director of The Parkinson's Institute, spoke on "New Treatment on Parkinson's and Non-Motor Issues" along with Helen Landsman, Certified Information & Referral Specialist at Avenidas. Here are a few notes from their presentations:

### Avenidas - Finding the Resource That Makes the Difference

Avenidas ([www.avenidas.org](http://www.avenidas.org)) runs a senior center in Palo Alto, runs a senior day health center in Mtn View, hosts support group meetings and caregiving classes, offers legal aid, offers a handyman service, and gives information to people seeking help for older adults. Helen Landsman and Shirley Lowler share the Information & Referral job at Avenidas. When I was looking for the inside story on assisted living centers in the Palo Alto/Menlo Park area, I called Avenidas. They periodically update and publish a guide to assisted living and skilled nursing facilities in San Mateo and Santa Clara Counties; it's called "Where to Live." You can buy a copy from Avenidas for \$7.50 (plus \$2.50 to have it mailed to you). Linda helped me snag a few extra copies of this booklet to lend out to group members. (I'll bring copies to the next support group meeting to lend out.) You can call Helen or Shirley (650/289-5433) if you need suggestions on an appropriate organization like Avenidas in your area (if you aren't in San Mateo or Santa Clara Counties). Helen also said that she and Shirley have become certified reverse mortgage counselors.

### The Parkinson's Institute - New Treatments on Parkinson's and Non-Motor Issues

Dr. Melanie Brandabur is the Clinical Director of The Parkinson's Institute. If I ever have the need to see a neurologist, I'd definitely try to get in to see her! She's got a great bedside manner. Here are the notes I took during her presentation and the Q&A, organized in order of declining interest (to those in the Atypical Parkinsonism world).

She said that if a PD patient has swallowing problems early on, the patient may actually have Atypical Parkinsonism. She said she would recommend that patient have a modified barium swallow study done to learn what's going on.

Drooling occurs because people forget to swallow.

Atropine (eye drops applied under the tongue) can dry out the mouth. This can be a problem because the mouth is already dry! It's best to give the person with PD hard candy or gum to put in their mouth. This will remind them to swallow. Also, a bottle of water next to the person with PD, and frequent reminders about drinking, will help the person swallow and keep the drool under control. PD can cause changes in secretions. Those with PD might have more cavities.

Exercise is VERY important. Research that is one or two years old shows that exercise may slow the progression of PD. She recommends the TV show "Sit and Be Fit" along with their exercise tape just for PD patients. She cautions people in using balance balls; she thinks these can be dangerous even for people with good balance.

Those with PD have a lack of motivation. This type of apathy may not be treatable. The lack of motivation seriously affects exercise. She encourages everyone to get into an exercise routine.

Anyone with a neurodegenerative condition should do whatever they can to avoid general anesthesia. Try to get local anesthesia. If you must have general anesthesia, get the minimal amount and insist that the anesthesiologist (an MD) be in the room during the surgery. (The anesthesiologist won't like this. But you have to insist.)

Up to 90% of those with PD are depressed. Often sleep problems are related to anxiety and depression. She prefers to treat this with an SSRI (eg, Paxil). She says that the depression associated with PD is "biochemical depression" (caused by reduced serotonin) that we need to treat biochemically (by adding serotonin).

She's not a big fan of nutritional drinks like Ensure. If these are consumed, they should be taken between meals, not during a meal. She thinks it would be better to drink a milkshake than Ensure.

Constipation is a very common problem. This is because with PD the transit time through the gut is slowed considerably. For constipation, try a "power pudding" or something similar for one week. Try something else if that doesn't work. It seems that the cures to this constipation battle are very individual. With PD, the muscles can't push out stool. Constipation can cause back pain. She recommends the prescription laxative Miralax.

Urinary "accidents" occur because the early warning system is gone. Bladder training is very important.

Staying hydrated is very important. It helps the constipation problem. Also, OH (orthostatic hypotension) is widely associated with PD. A lack of hydration can make the OH worse.

There was a very small study of CoQ10 (1200mg) in early PD patients that had promising results. Unfortunately CoQ10 is very expensive. You need to take at least 1200mg to make it worthwhile. Look around on the internet for deals on CoQ10.

Everyone should eat fish, keeping in mind the mercury problem. If you've got fish oil capsules that smell fishy, throw them out.

Weight loss is associated with PD. We don't know why. Perhaps it's related to depression, dyskinesia, or feeling full (because the stomach is working very slowly so it may remain full for a long time).

She talked about a variety of sleep-related problems. REM Sleep Behavior Disorder (RBD) is related to PD. This is treatable. RLS (Restless Leg Syndrome) might be a sign that medication is wearing off. The primary symptom of obstructive sleep apnea is snoring. A CPAP mask is the best treatment. If one mask doesn't work, keep trying masks. Night sweats can be from medication wearing off.

Sexual dysfunction due to PD is treatable with a drug like Viagra. Speak to your primary care physician about this.

She's a big fan of the booklets put out by the National Parkinson Foundation. (Robin's note: You can find these at [www.parkinson.org](http://www.parkinson.org); then click on Library and Publications.)

She recommends that if you want to stay up on the latest in PD research (or research on any medical subject), go to Medline Plus. (Robin's note: Medline Plus is a great resource for explaining how certain tests are performed. You can find it at <http://www.nlm.nih.gov/medlineplus/>)

It costs \$900 million to bring a drug to market.

The main side effect of drugs like Azilect (the new PD drug) is that they cause a hole in your pocket. Azilect is an add-on to Sinemet or for newly-diagnosed PD patients. There's lots of info on the label about what other drugs you shouldn't take Azilect with. Anecdotally, she believes that one patient's apathy is improved as a result of Azilect. She is hopeful that further study of Azilect will show that the disease progression of PD has been slowed.

She attended a conference in 1997 where it was announced that 5 medications in patch form were being developed for PD. One of those 5 is finally coming out. It's called Neupro. It will be very expensive. It's a dopamine agonist.

Amantadine can cause a skin rash. The yellow Sinemet can also cause a skin rash (though this is rare).

Aricept, Namenda, and Exelon - all AD drugs - work well for PD. Some of their labels are being changed to indicate that "this drug is indicated for PD." This way, insurance companies may now pay for this drug for those with PD.

*Robin Riddle is the leader of the San Mateo Atypical Parkinson's Caregivers support group. Thanks, Robin!*

### **In Honor**

PPSG recently received gift donations honoring the following individuals: John J. Tully, June Miller, Leon Rosenthal's 80<sup>th</sup> birthday, and Manuel S. Perez.

### **In Memory**

PPSG recently received gift donations in memory of the following individuals: Elaine Bailey, Yok-Yuet Tsui Chao, Jack Henning, Carolyn G. Hoyt, Mickey Mendoza, Harold Moates, Elayne Reed, Dino Restelli, Fred Smyers, N. Sheklian, Liz & Eric Southwood, and Ray C. Tylutki.

**Thank you so much for your donations!** Please use return address labels, to help us acknowledge your donations properly. Your generous contributions go to support newsletters, education and community awareness of Parkinson's disease.

## **PPSG Board Meetings**

You are welcome to drop by our board meetings and share ideas with us! We meet on the **3rd Monday** of the month between **1:30 and 3:30 PM** at the Parkinson's Institute. To confirm meeting dates and time, please call us at 408.734.1593. If you are planning to attend, please call Charmaine Eng at 408.723.8116 (dial \*82 before the number).

If you would like to be removed from our mailing list or know someone who would like to be included, please take a minute, call us at **408.734.1593**, or e-mail [ppsginfo@yahoo.com](mailto:ppsginfo@yahoo.com), and let us know.

PPSG has been looking for ways that will help our readers find a book or books that can help them deal with their problems more effectively. We do not consider ourselves to be expert critics, but we will try to shed more light by quoting the authors and publishers. This and future newsletters will present what we call *snapshots* of at least twenty books and booklets. The list is based on books that are available in one of the Barnes & Noble and Borders stores, and a group of free booklets from the National Parkinson Foundation.

## **BOOKS – A PPSG Snapshot**

### **The Parkinson’s Disease Treatment Book**

From front cover:

The Parkinson’s Disease Treatment Book, Partnering with Your Doctor to Get the Most from Your Medications

“Easy to understand guidance on the right drugs and doses to control tremors, stiffness, and slowness”, “Effective diet and nutrition strategies”, “Advice on treating anxiety, depression, sleep problems, dizziness, and sexual dysfunction”

J. Eric Ahlskog, M.D., Mayo Clinic Parkinson Specialist  
Oxford University Press

Copyright 2005, 532 pages, hardcover, \$35.00

Part One - Basic Facts about the Brain and PD  
Part Two – PD: Diagnosis and Prognosis  
Part Three – Distinguishing PD from Other Disorders  
Part Four – The Cause and Progression of PD  
Part Five – The Movement Problems of Parkinson’s Disease: Medication Rationale and Choice  
Part Six – Beginning Treatment of Parkinson’s Disease: Medication Guidelines  
Part Seven – The Early Years on Medication  
Part Eight – Later Medication Inconsistency: Motor Fluctuations and Dyskinesias  
Part Nine – Other Treatment Problems: Not Just a Movement Disorder  
Part Ten – Nutrition, Exercise, Work, and Family  
Part Eleven – Surgery and Procedures for Parkinson’s Disease: Present and Future  
Part Twelve - Parkinson’s Disease Information Sources  
Glossary – 8 pages  
Index – 19 pages

From back cover: The first of four commentaries  
“Eric Ahlskog of the Mayo Clinic is one of the country’s leading experts on Parkinson’s Disease.. His book, The Parkinson’s Disease Treatment Book, is comprehensive and informative and will be a welcome addition to the library of patients with Parkinson’s

Disease and their caregivers.” Nathan Slewett,  
Chairman Emeritus, National Parkinson Foundation

## **BOOKS - A PPSG Snapshot**

### **The Parkinson’s Handbook**

From front cover:

The Parkinson’s Handbook  
Dwight C. McGoan, M.D.

“An inspiring, practical guide for patients and their families by a Mayo Clinic surgeon with Parkinson’s Disease”

Copyright 1990, 175 pages, paperback, \$13.95

Figures and Exhibits

Preface

Chapter 1 The Onset of Parkinson’s

The Onset

Organization of This Book

My Unique Advantage as Author of This Book

Chapter 2 What Goes Wrong in Parkinson’s

Normal Muscle Control

Abnormalities in Parkinson’s

Who Gets Parkinson’s

Chapter 3 Treatment

Drug Therapy

Drug Therapy is Only Palliative

Prospects for Drug Therapy

My Treatment Schedule; The Daily Drug Holiday  
Surgery

Chapter 4 Fighting Back

My Amazing Evening Walks

Organizing Resources

Joint, Muscle, and Posture Preservation

Tremor

Muscular Rigidity

Problems in Moving About

Problems with Other Body Systems

Chapter 5 The Importance of Attitude

Glossary – 10 pages

Suggestions for Further Reading

Index – 14 pages

From back cover: The first of five commentaries:  
“Reading this book ought to be a prerequisite for all persons involved in coping with Parkinson’s Disease, be they patients, caregivers, or health care professionals.”

*A special thank-you to Allan Daily, the PPSG Treasurer, for his contribution on the “snapshot” project. Our members will find his researched information very helpful. Thanks very much, Allan!*

## A PPSG Book Snapshot 100 Questions and Answers

From front cover:

100 Questions and Answers

About Parkinson's Disease

by Abraham Lieberman, MD

with Marcia McCall

What is Parkinson's Disease?

What Causes Parkinson's Disease?

What are the primary symptoms of Parkinson's Disease?

Why is Parkinson's Disease called a movement disorder?

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### Part 1: Some Basic Questions

?? What is Parkinson's disease?

?? What causes PD?

?? Will I die from PD?

### Part 2: Tell Me More

?? What are the main symptoms of PD?

?? I have an appointment with a neurologist.  
What should I expect?

?? Do these symptoms always mean PD? Could it be something else?

?? Why is it called a "movement disorder"?

?? I heard PD is a "progressive" disease. What does that mean?

### Part 3: Treatment

?? What is the goal of treatment?

?? What drugs are used to treat PD?

?? Why start with a dopamine agonist?

?? Do agonists slow progression of PD?

### Part 4: Social and Psychological Aspects of PD

?? What do I tell my grandchildren?

?? Do I tell my boss?

?? Will I be able to drive?

?? What will become of my social life?

?? What about sex?

### Part 5: Progression

?? What stage am I in?

?? How do I know if my disease is progressing?

?? Why do I fall?

?? I can't sleep. Is this PD?

?? Is depression part of PD?

?? Will I lose my mind?

### Part 6: Surgery for PD

?? What is a thalamotomy?

?? What is pallidotomy?

?? What is deep brain stimulation (DBS)?

?? What are stem cells?

### Part 7: Alternative Approaches to PD

?? Should I exercise?

?? What should I eat?

?? Why am I losing weight?

?? Do I need vitamins?

### Part 8: Making the Most of Life with PD

?? Why me? What did I do to deserve PD?

?? Can I make my home safe?

?? Will I be able to walk?

?? Should I take a drug holiday?

?? How can I become less anxious?

### Part 9: Hope

?? How long before a cure?

?? What are my chances of developing PD?

?? Where can I get more information about PD?

### Appendix

A list of web sites, organizations, and literature to help Parkinson's Disease patients and their families find additional resources on general and specific topics related to Parkinson's Disease.

Glossary 6 pages

Index 7 pages

From inside back cover:

Abraham Lieberman, MD, an internationally recognized expert on Parkinson's Disease, is the author of six books on the topic, including *Shaking Up Parkinson's Disease: Fighting Like a Tiger, Thinking Like a Fox* (2001). He is board certified in neurology and psychiatry, is a Fellow of the American Neurological Association, and the Movement Disorder Society. Dr. Lieberman is National medical Director of the National Parkinson Foundation (NPF) and Professor of Neurology at the University of Miami. His widely popular manual on Parkinson's disease has been translated into five languages, with more than one million copies distributed worldwide. Dr. Lieberman's interactive web-site, [www.parkinson.org](http://www.parkinson.org), answering questions about Parkinson's Disease, is viewed by 10,000 people with PD each day.

### Disclaimer

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## PPSG Support Groups 408.734.1593

### NORTHERN AND EAST-BAY REGION

**Berkeley** 3<sup>rd</sup> Mon 10-12 North Berkeley Senior Center, 1901 Hearst Av, Roddy Raikow 510-231-1998 or Mitzi Cahn 510-527-9075 **Fremont** 4<sup>th</sup> Mon 7:00 pm Fremont Senior Center 40086 Paseo Padre Parkway, Lettie Webb 510-656-6393 or Bob Coon 510-794-7988 **Fremont Caregivers** Contact Nancy Rothschild, Caregiver Project Coordinator, 510-574-2035 **Marin County** 4<sup>th</sup> Tue most mo. 2-4 Redwoods Auditorium 40 Camino Alto, Mill Valley, Gloria Rashti 415-381-6680, Redwoods' 415-383-2741 **Mt. Diablo Parkinson's Network General Meetings** 2<sup>nd</sup> Sat 10-12, Grace Presbyterian Church, 2100 Tice Valley Blvd, Walnut Creek, Nancy Walls, 510-236-7065, Philip Wheeler, 510-527-3588, or Ronalee Spear, 925-284-2189 **Oakland** 1<sup>st</sup> Thur 1:30-3:30 Easter Seals Bay Area, 180 Grand Av, Suite 300, Robert Lemon 510-526-2078 **Petaluma** Last Sat 1:30-3:30 Sunrise of Petaluma, 815 Wood Sorrel Dr, John & Mamie Strong 707.763.3522 **Pleasanton Tri-Valley** 2<sup>nd</sup> Sat 10-12, Senior Center, 5353 Sunol Blvd, Norm & Jackie Bardsley, at 925-244-1231, or 925-831-9940 **Roseville** 1<sup>st</sup> Tues 1:30-3:00 Roseville Maidu Comm Ctr, 1550 Maidu Drive, Linda Krisa 916-261-1321 **San Leandro** 1<sup>st</sup> Thur (no meetings Jul & Aug) 10:00, San Lorenzo Community Church, 945 Paseo Grande, San Lorenzo, Harry Santi 510-351-3224, Noma Zeff 510-663-6435 **Sonoma County** 1<sup>st</sup> Sat (not Jan, Jul, Sep) 1-3, First Congregational Ch, 2000 Humboldt St, Santa Rosa, Ron & Colleen Trowse 707-526-4373 **Vallejo** 3<sup>rd</sup> Mon (except 2nd Mon, Jan & Feb) 2:00 Kaiser Medical Center, 975 Sereno Drive, Evelyn Fox 707-644-3390

### PENINSULA REGION

**Daly City** 1<sup>st</sup> Tue 3-4 Doelger Senior Center, 101 Lake Merced Blvd, Leonard Ke 415-587-1285 **Los Altos Young Parkinson's Support Group** 2<sup>nd</sup> Sat 10-12, United Methodist Ch/Los Altos, Foothill at Magdalena, Dean Prescott 408-738-2505 or dean53@yahoo.com **Magnolia-Peninsula** 2<sup>nd</sup> Thur 1:30 main conference room Magnolia Apart, 201 Chadbourne Av, Millbrae, Leon Rosenthal, 650-348-3480 **Palo Alto** 2<sup>nd</sup> Wed 2:00-3:30 Avenidas Senior Center dining room, 450 Bryant St, Linda Chen 650-254-0906, for directions call 650-289-5400 **Redwood City** 3<sup>rd</sup> Fri 1-2:30, (No meetings Aug, Nov, Dec) 749 Brewster Avenue, Sequoia Hospital health & Wellness Center, Tom Constantino or David Shein 650-367-5998 **NEW San Francisco Caregivers** Thur (varies) 12-1 VAMC Parkinson's Ctr conf room, Susan Heath & Aliza Benditsky RSVP 415-379-5530 **San Mateo Atypical Parkinsonism (PSP, LBD, MSA, CBD) Bay Area Caregivers** Sundays 5-7 about every 6 weeks, Mimi's Café 2208 Bridgepointe Parkway, San Mateo, Robin Riddle 650-233-9277 or riddle@stanfordalumni.org **San Mateo Caregivers** 1<sup>st</sup> Wed 2:30-4:30 Ellsworth Room 100 San Mateo Dr., Call Carol Hoffman, Mills Health Center 800-654-9966 **Sunnyvale** 2<sup>nd</sup> Wed 1-3 First United Methodist Ch, 535 Old San Francisco Rd, Phyllis & Henry Ng 408-733-5648 **YOPD** (Young Onset Parkinson's Disease) 2<sup>nd</sup> Tue 6:30-8:00, Board Room, Lucille Packard Child Hosp, 725 Welch Road, Palo Alto, Martha Gardner 866-250-2414

### SOUTHERN REGION

**Fresno, North** 2<sup>nd</sup> Saturday, 10 am, Joaquin valley Rehab Hospital, 7173 N. Sharon Ave; max Robinson 599-226-2673  
**Hollister** 1<sup>st</sup> Tue 1:30-3:30 First Presbyterian Ch, 2066 Cienega Road, Shirley Kennedy 831-637-3839 or John Skinner 831-637-6755 **Merced** 4<sup>th</sup> Thur 10AM (Nov 17, Dec no meeting) Mission Gardens 1450 E. 27<sup>th</sup> St, Amie Marchini 209-384-3300 **Modesto** 3<sup>rd</sup> Wed 1:30-3:00 Centenary United Methodist Ch, Fireside Room 1911 Toyon Av, JoAnn & David Ryan 209-529-

5643/davejoann@sbcglobal.net **Monterey** 3<sup>rd</sup> Mon 2:30-4:00 SHARE Room, Monterey Adult School, 200 Coe Av, Seaside, Helen Garrett 831-657-4241 or Kathy Warthan 831-372-7510 **Pine Grove** 1st & 3<sup>rd</sup> Thurs 2-4 Calvary Chapel Patio Bldg, 18400 ridge Road, Sarah Johnson 209-296-3522 **Salinas** 4<sup>th</sup> Wed 2:00-3:30 Salinas Adult School, 20 Sherwood Place, Sherry Whitcomb, 831-796-6920 **San Jose-Berryessa** 1<sup>st</sup> Wed 1:00-2:30 Berryessa Community Center, 3050 Berryessa Rd, Bob & Jane Pomeroy 408-263-8485 **San Jose Caregivers** usually 4<sup>th</sup> Wed 1:30-3:30 St Francis Episcopal Church, 1205 Pine Ave, Charmaine Eng 408-723-8116 **San Jose-Willow Glen** 1<sup>st</sup> Fri 10-12 St Francis Episcopal Church, 1205 Pine Ave, Joan Lorentson 408-997-7009 **Santa Cruz** 1<sup>st</sup> Wed 12:30-2:00 St. Stephen's Lutheran Church, 2500 Soquel Ave, David Donahoe 831-479-4485 **Saratoga** 3<sup>rd</sup> Tue 2-4 19449 Via Real, Lois McPherson 408-867-1807 **Tulare-Kings** 1<sup>st</sup> Fri 10:30 Visalia United Methodist Church, 5200 W. Caldwell Av, Mary Dickerson 559-622-9044, Church Office 559-627-1660 **(FORMING) Turlock** Donald Jackson 209-606-9127

### Upcoming Local Support Group Meetings

#### Fremont

Our September 25 speaker was Gene Osofsky, Attorney at Law, and his topic was "Basic Estate Planning, Protecting Your Assets, and Planning for Long Term Care."

In October our speaker will be Margie Dino, Palo Alto Medical Clinic, who will speak on CPR and the Heimlich Maneuver.

#### Magnolia-Peninsula

Thursday, October 25: Dr. Arnold Greenberg, prominent SF neurologist, currently working with some new medications in trials.

Thursday, November 9, Dr. Carmen Schroder, psychiatrist, of Stanford will discuss sleep and Parkinson's.

December: No meeting. Will resume in January.

PLEASE NOTE: the October meeting will deviate from our normal pattern. It will take place at the Magnolia BUT at 7:00 pm until 8:30 pm, rather than our normal afternoon session. All are welcome. We hope you can come.

#### Redwood City

Ginny Morrow of the Peninsula Gastroenterology Group joined us at the September 15 meeting at our new location, 74 Brewster, in downtown Redwood City. Ray Lang, President Emeritus, chaired this meeting.

Carol Hawthorne, an Occupational Therapist, Home Based Primary Care specialist, will join us on October 20. She will discuss an important topic, home safety. Bring your questions.

New location 749 Brewster is two blocks west of Veterans Blvd., or about four blocks east of El Camino Real. It's less than two blocks from the multi-story San Mateo County Hall of Justice Building. It is the new Sequoia Hospital Wellness Center in Redwood City. If exiting from US 101, take the Redwood City Whipple exit.

### **San Jose – Willow Glen**

Mzumo Kudumu was guest speaker at our September meeting. He discussed the ancient healing exercise Tai Chi and demonstrated while the 45 attendees participated. Mzumo answered questions afterward, and everyone enjoyed and appreciated his presentation. He and Jane Kerr co-founded Kujiweza Healing Arts Institute and offer classes for people with Parkinson's disease and other movement disorders. Classes are at The Villages, Stanford Medical Center, and The Terraces in Los Gatos.

Programs for upcoming meetings will be:

October 6 – Randy Hoffman, Speech Therapist, The Parkinson's Institute.

November 3 – Pat Kearney, Dietitian, Stanford Medical Center.

December 1 – Evergreen Community College Choir, led by Betty Owen.

Members were happy to welcome back Betty Havens, who is still convalescing. She and her husband started this support group in 1993.

The San Jose Support Group meets on the 1st Friday of the month, from 10 AM – 12 noon, at St. Francis Episcopal Church, 1205 Pine Avenue, San Jose. For information please call Joan Lorentson at 408.997.7009.

### **San Leandro**

The San Leandro Parkinsons Support Group meets on the 1st Thursday of every month, except July and August. The next meeting is on Thursday, October 5, from 10 AM to 12 PM. Exercise time will be 10 to 10:30. The American Red Cross will present a program about disaster preparation, and someone from the Alameda County Fire Dept. will describe the Vial of Life. The meeting is at the San Lorenzo Community Church, at 945 Paseo Grande, San Lorenzo. For more information call Harry Santi at 510.351.3224.

### **David "Dave" Russell**

01/13/1924-09/25/2006

Dave Russell, 82, died from complications brought on by liver cancer and Parkinson's disease, on September 25, 2006 at his home in Redwood City. Dave was born in Los Angeles on January 13, 1924 and was adopted by Hazel Kaye and Jack Russell. He attended the Jerry Voorhees School and graduated from Covina High School in 1941. Dave proudly served as a signalman in the US Navy during most of the major battles of WWII. He graduated from UC Berkeley with a Bachelor's degree in 1950.

Dave worked at Lenkurt Electric for 28 years, and helped many start-ups in Silicon Valley as a financial controller. After his retirement, Dave served on the board of the Parkinson's Patients Support Groups, Inc. (PPSG). He also loved gardening, traveling, golf and exercising with his friends at the Cardiac Therapy Foundation in Palo Alto. Dave and his family lived in Portola Valley for 38 years before moving to Redwood City in 2002.

Dave survived his wife, Marie, who died in 1997, as well as his son-in-law, Woody Lawrence, who died this Spring. He is survived by his children: Steven, and Alan, Alan's wife Stephanie, daughter Marilyn Lawrence, and grandchildren C. J. and Nico Russell, and Justin and Jason Lawrence, and his very special friend and companion for the past six years, Wanda Iverson.

A celebration of Dave's life will be held on October 7, 2006, from 11:00 AM, to 3:00 PM at his home, Redwood City, CA. In lieu of flowers, Dave requested memorial contributions be made to Parkinson's Patients Support Groups, Inc. (PPSG), 1170 Morse Avenue, Sunnyvale, CA 94089-1605.

We are very sad to announce that PPSG has lost our beloved Dave Russell, a Board Member, dear friend, and dedicated volunteer. Dave joined PPSG about six years ago, and he was our Treasurer. Dave always shared his good sense of humor, enthusiasm, charm, and kindness. He was an honorable man with integrity and had made lots of contributions to PPSG. Good-bye, Dave! We will miss you!

We would also like to send our deepest sympathy to Dave's family and his special friend, Wanda Iverson. Steven Russell, one of Dave's sons, and Wanda are friends and dedicated volunteers for PPSG. We appreciate all their on-going support and special contribution!

## Gene Therapy Clinical Trial at UCSF, An Update

The Parkinson's Disease Clinic & Research Center at the University of California, San Francisco is now seeking a 2nd group of patients for the clinical trial: Phase I Safety Study of Intrastratial Infusion of Adeno-Associated Virus Encoding Human Aromatic L-Amino Acid Decarboxylase (AAV-hAADC-2). This 2nd group of volunteers would be receiving a higher dose of the investigational drug. Patients who undergo the surgical procedure would continue to take L-dopa.

For more information, please call the research nurse Rowena Mah at (415) 476-0947 or email her at [Rowena.Mah@ucsf.edu](mailto:Rowena.Mah@ucsf.edu).

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Le Sotir

We would like to welcome **Carla Gwosden**, as our new **Secretary**. Carla was once our PPSG Chairman. Welcome back, Carla! We are so happy that you come back to join us. Our previous Secretary, **Doris Gilmore**, recently moved to the State of Washington. Farewell, Doris! Thank you very much for your help!

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



Parkinson's Patients Support Groups, Inc.  
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