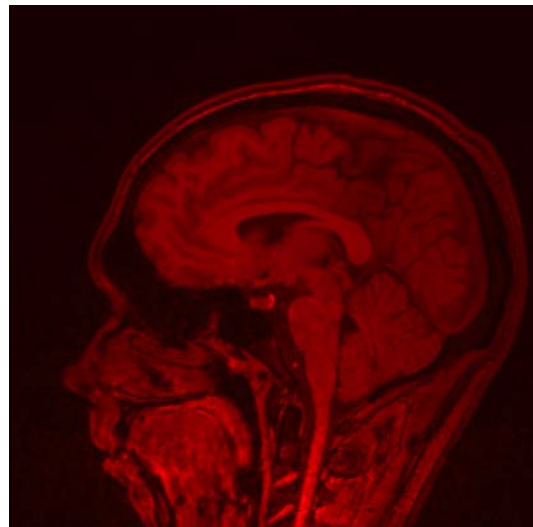
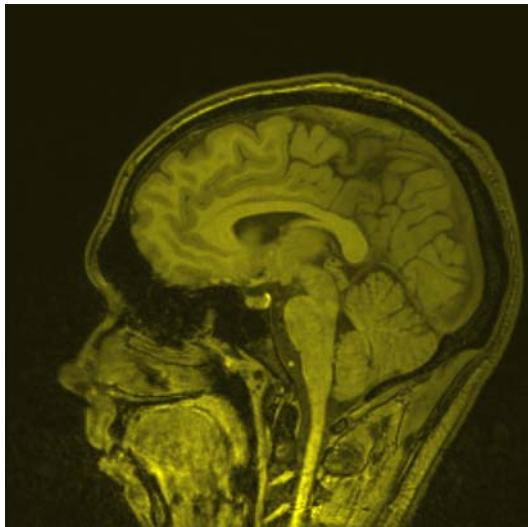
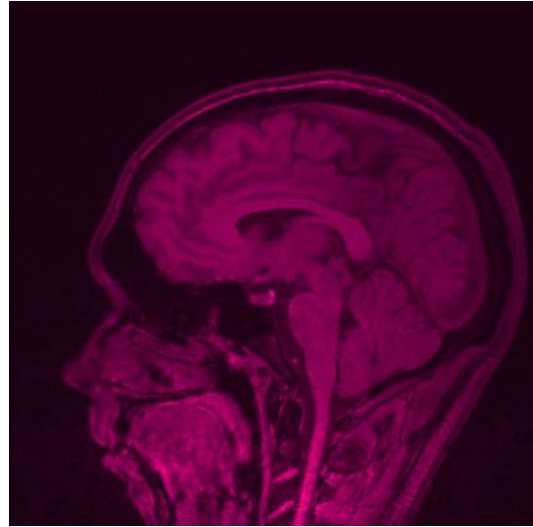
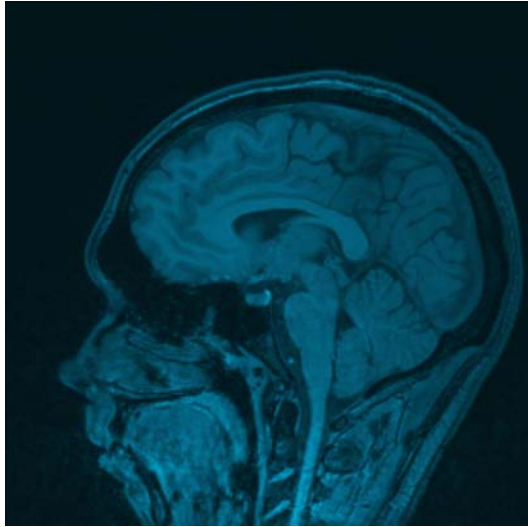


A PATIENT'S GUIDE TO PARKINSON'S DISEASE SURGERY



**DEPARTMENT OF NEUROLOGICAL SURGERY
THE OHIO STATE UNIVERSITY MEDICAL CENTER**

You may be reading this pamphlet because you or someone you love has been referred for possible surgical intervention for Parkinson's disease. You are not alone, and will require a dedicated medical team for help.



The National Parkinson Foundation estimates there are currently 1.5 million Americans affected with Parkinson's disease. Approximately 60,000 new cases are diagnosed each year. While the condition usually develops after the age of 65, 15% of those diagnosed are under 50.

WHAT IS PARKINSON'S DISEASE?

Parkinson's disease is a disorder that affects nerve cells, or neurons, in a part of the brain that controls muscle movement. In Parkinson's, neurons that make a chemical called dopamine die or do not work properly. Dopamine normally sends signals that help coordinate your movements. No one knows what damages these cells. Some symptoms of Parkinson's disease may include

- Tremors - trembling of hands, arms, legs, jaw and face
- Rigidity - stiffness of the arms, legs and trunk
- Bradykinesia - slowness of movement
- Balance and coordination problems

As symptoms get worse, people with the disease may have trouble walking, talking or doing simple tasks. They may also have problems such as depression, sleep problems or trouble chewing, swallowing or speaking.

WHEN IS IT APPROPRIATE TO CONSIDER SURGICAL INTERVENTION FOR PARKINSON'S DISEASE?

The first line of treatment for Parkinson's disease consists of medications aimed at managing the symptoms of the disease.

As the disease progresses some patients may develop wearing off spells. During these "off" periods they will have significantly more trouble with movement and are difficult to treat. During the "on" periods they will have good effect from their medications and they are able to move better, with less stiffness.

Other patients suffer from dyskinesias, which usually present after long-term use of levodopa therapy. Dyskinesias consist of involuntary writhing and twisting movements typically of the limbs. These present during the periods when levodopa concentration is higher in the blood.

Most patients are able to achieve a good quality of life with medications only. When medication adjustments are no longer improving mobility and/or causing intolerable side effects it is a good time to consider surgical intervention.

WHO IS THE IDEAL PATIENT CANDIDATE FOR PARKINSON'S DISEASE SURGERY?

Patient selection is an important component to the success of surgical treatment. The ideal patient has the following characteristics:

- Typical Parkinson's disease with symptoms that respond to levodopa medication – even if only briefly.
- Uncontrollable dyskinesias
- Disabling motor fluctuations – "on/off" periods
- Disabling tremors
- Good general health

WHAT ARE THE DIFFERENT TYPES OF SURGICAL THERAPY AVAILABLE FOR PARKINSON'S DISEASE?

The first surgical procedures developed were "ablative or brain lesioning" procedures. In lesioning, a surgeon uses a heat probe to destroy a small area of brain tissue that is abnormally active in Parkinson's disease. The advantages of these procedures are they do not require placement of wires in the brain, and their result is permanent. The disadvantages include: no ways to adjust their effects for better symptom control, irreversible nature, and in general, not safe to be performed on both sides of the brain. Today we

have a newer and reversible form of surgery for Parkinson's Disease which is called deep brain stimulation(DBS).



WHAT IS DEEP BRAIN STIMULATION?

Deep brain stimulation is achieved by surgically implanting leads(electrodes) that are targeted to specific portions of the brain. This device uses electrical stimulation to help manage the disabling symptoms of Parkinson's disease. Electrical stimulation is supplied by a battery-operated device called a pulse generator, and is surgically implanted under your skin near your collarbone. An extension, which is connected to the pulse generator, is surgically tunneled under the skin, and connects to one or two leads placed in the brain. All components of the deep brain stimulation system, including the pulse generator, extension and leads are all surgically implanted by a neurosurgeon.

After implantation has successfully occurred, adjustments to the DBS will be made by a physician or a nurse to maximize Parkinson's symptom relief. Adjustments to the DBS are performed non-invasively through the use of a handheld programming device.



Hand held programming device

www.medtronic.com

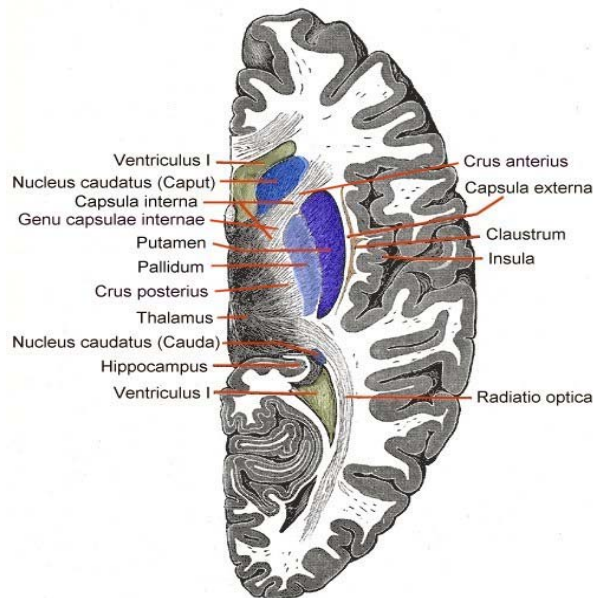
HOW DOES DEEP BRAIN STIMULATION WORK?

Deep brain stimulation works by supplying electricity to specific areas of the brain targeted by your neurosurgeon. Electrical stimulation is believed to lessen the symptoms of Parkinson's disease by interfering with, or stopping the electrical signals thought to be causing the disorder. These areas of the brain are mapped out prior to surgery through the use of diagnostic testing.

WHAT ARE THE DIFFERENT BRAIN TARGETS FOR DBS IN PARKINSON'S DISEASE?

There are three possible target sites in the brain that may be selected for placement of stimulating electrodes: the globus pallidus (GPi), the subthalamic nucleus (STN), and the thalamus. These structures are some of the centers that play a very important role in movement control in Parkinson's Disease.

Thalamic stimulation is only effective for tremor. Stimulation of the globus pallidus or subthalamic nucleus, in contrast, may benefit not only tremor but also other parkinson's symptoms such as rigidity (muscle stiffness), bradykinesia (slow movement), and gait problems. DBS of the globus pallidus or subthalamic nucleus is the obvious choice for most patients because of the greater range of symptom treatment. The most appropriate target will be determined by your neurosurgeon depending on your symptoms.



DIAGNOSTIC TESTS AND PROCEDURES

Treatment options for Parkinson's disease surgery will depend largely on specific symptoms. Additional diagnostic tests may be necessary to accurately determine final location for lead placement and include:

- Computed Tomography (CT): A CT scan provides a two-dimensional map of tissues and organs in the body using an x-ray beam
- Magnetic Resonance Imaging (MRI): The MRI creates a detailed picture of the brain and surrounding structures using a powerful magnetic field
- Neuropsychological Testing: Screening tool used to evaluate cognitive and emotional status prior to surgery.
- Bone Fiducials: An invasive preoperative procedure consisting of a set of five to six small screws anchored in the skull which provides a map of the brain. Bone fiducials guide final electrode placement during surgery.

WHAT HAPPENS DURING INVASIVE TESTING?

An appointment will be made for you to come to your neurosurgeon's office to have bone fiducials placed. Local numbing medicine will be used to make the procedure more comfortable for you. It will take approximately 30 minutes and you will be asked to have a CT and MRI performed immediately following the procedure.

BEFORE SURGERY

Even before your surgery starts, the planning begins to help make your hospitalization comfortable and your recovery safe. A few things will need to be done before your surgery:

Pre-operative assessment: In addition to the tests mentioned before, you will have an exam by the anesthesia team at the Outpatient Pre-Operative Assessment Center (OPAC). The purpose of this exam is to review your health conditions and risks of surgery. You will also be asked to consent for anesthesia. The OPAC is located at Martha Morehouse Tower, 2050 Kenny Road, Columbus, OH 43221, phone 614-366-4087.

Bring the name, telephone number and address of your Primary Care Physician in order to facilitate post-operative care.

Medication review: Bring a list of your medications (include dose, times taken) or the actual bottles to your OPAC appointment as well as on the day of surgery. The OPAC team will review them and make any recommendations to temporarily hold medications before surgery. These would include aspirin, aspirin-containing products, blood thinners, anti-inflammatories.

Notify surgeon's office if you develop a cold, sore throat, cough, fever or illness before surgery.

If you smoke cigarettes, it is advised you stop smoking completely or decrease the amount you smoke. Smoking adversely affects healing of the bone and incision. As a result will delay or impede the recovery process following your procedure.

Make sure you get plenty of rest, eat healthy and drink plenty of clear fluids before your surgery. Post-operative pain medications can cause constipation. You may consider taking stool softeners for a few days prior to your surgery to make sure that you are not uncomfortable following surgery and during your hospitalization. Post-operative pain medications can cause constipation.

There are certain precautions that should be taken before your surgery including:

- If you are on blood thinners you should stop taking them a week before your surgery.
- Do not eat or drink anything after midnight the day of your surgery.
- You will be given soap that you should wash with twice the day before your surgery.

DAY OF SURGERY

On the day of surgery, you should not eat or drink after midnight. You may have a few sips of water to take any of your regular medications unless you have been instructed otherwise. Also please bring a list of any medications you are currently on along with the dosage you are taking, it would be appreciated if this could be typed.

You should plan on arriving to the hospital **two hours** before your surgery is scheduled to begin. After you arrive at the hospital, you will be asked to check in to the admitting department. From there, you will be transported to the ambulatory surgery unit (ASU). The ASU will ensure that all paperwork, laboratory work and x-ray imaging has been completed prior to your surgery. Approximately 30 minutes prior to your surgery, a member of the anesthesia team will meet you in the pre-operative waiting area to talk to you about your health and to insert intravenous (IV) catheters and a foley catheter.

Your family members will be asked to wait in the designated waiting area. A volunteer and monitor will update them throughout the waiting period.

STEP ONE: 48 to 72 hours after the bone fiducials have been inserted, you will be asked to come back to the hospital for surgical placement of the electrodes. You should plan on arriving to the hospital **two hours** before your surgery is scheduled to begin. After you arrive at the hospital, you will be asked to check in to the admitting department. From there, you will be transported to the ambulatory surgery unit (ASU). The ASU will ensure that all paperwork, laboratory work and x-ray imaging has been completed prior to your surgery. Approximately 30 minutes prior to your surgery, a member of the anesthesia team will meet you in the pre-operative waiting area to talk to you about your health and to insert intravenous (IV) catheters.

STEP TWO: A member of the anesthesia team will put you to sleep before your surgery begins. Your neurosurgeon will use results from your CT and MRI to determine final location of the leads. In some occasions he/she may perform additional testing inside the operating room to confirm optimal position of leads.

STEP THREE Once the lead is in place you will be awakened during surgery. At this point you will be asked to perform certain simple exercises in order to assess improvement in motor function and tremor. You will also be asked some questions regarding your vision and/or any abnormal sensations. This is all done to ensure optimal placement of the lead with minimal side effects from stimulation. You will be put back to sleep once this portion of surgery is over.

If you are having leads placed in both sides of your brain, at this point steps 2 and 3 will be repeated on the opposite side.

STEP FOUR: After lead placement is completed and you have awakened from anesthesia, you will be taken to the Surgical Intensive Care Unit (SICU) for close neurological monitoring. A typical hospitalization will last one to two days. Two weeks after your

leads are placed, you will return to the hospital on an outpatient basis to receive surgical placement of the pulse generator near your collarbone,

STEP FIVE: You will be asked to see your neurology team 4 weeks after surgery, at which time programming via the handheld device will occur. The programming process may require multiple visits with your neurologist to optimize your DBS results.

AFTER SURGERY

Immediately following surgery, you will be taken to the post-anesthesia care unit (PACU) to recover from your anesthesia for approximately 1-2 hours. Once you have recovered, you will be transported to the neurosurgical nursing floor where your family will be able to meet you. A nurse and patient care assistant will help get you situated in your room.

- Within a few hours after surgery, you should begin to drink fluids on your own. Your foley catheter used during surgery should no longer be required and will be removed. You will need to ask your nurse or patient care assistant for help to walk to the bathroom.
- You may feel nauseated after surgery. Your nurse can provide you with anti-nausea medications.
- You will have an incision with sutures, staples or steri-strips that will be covered by a dressing. This will be left on for one day. Your surgery team will remove it after one day. You will be given instructions on how to take care of this at home. Generally, the area should be kept clean and dry. You should notify your surgery team of any discharge, odor, redness, warmth or opening to this area.
- Your home medications will be restarted according to your home schedule.
- You will have pain following surgery. We will attempt to keep you as comfortable as possible with appropriate pain medications. You will be asked to rate your pain so that we can measure any changes or effects of pain medications.

Your successful recovery from surgery will require many people working together, including you! Here are some of the responsibilities each person will have:

Surgeon/Nurse Practitioner

- Examine patient daily for wound appearance, side effects of surgery and physical functioning
- Review health changes since previous day
- Communicate orders to nursing staff
- Prepare discharge instructions, prescriptions
- Respond to questions from patient/family

Nurse/Patient Care Assistant

- Regular assessments of vital signs, activity levels, nutrition
- Manage IVs, foleys
- Monitor and address pain issues
- Assist patient to sit in chair or walk to bathroom or on floor
- Begin patient teaching related to home care
- Communicate with surgical team for changes to health
- Respond to questions from patient/family

Physical Therapist

- Assess current physical status
- Recommend appropriate safe environment at discharge, either home or rehabilitation center
- Assist with getting patient out of bed as soon after surgery as possible
- Respond to questions from patient/family

Patient Care Resource Manager/Social Worker

- Prepare discharge paperwork, including instructions and recommendations
- Assist with any discharge referrals recommended by the team
- Coordinate any placements to skilled nursing facilities or acute rehabilitation centers
- Answer questions regarding insurance, disability and income concerns
- Provide coping strategies for impact of surgery on you and your family

Patient/Family

- Inform team of pain issues related to surgery
- Avoid laying in bed throughout your hospitalization
- Attempt to walk with assistance throughout your hospitalization
- Listen to and follow surgical team recommendations
- Ask questions related to safety, pain, function to surgery team

AFTER HOSPITAL DISCHARGE

You will be discharged when the medical team, including yourself, feel that you can safely continue recovering outside of the hospital. On average, simple spine procedures can be 1-2 hospital days, complex spine procedures may be 2-4 hospital days. This does not always mean that you are pain-free or that you are able to return home. Most people are tired when they leave the hospital. Every day should get a little better once you are discharged.

Your discharge paperwork will have your follow-up appointments listed.

Care of your incision

Your incision may be slightly red around any staples or sutures. This is normal. You will be given instructions about when and where to have these removed. Some patients will have their primary care providers remove them. Be sure to call their office before going in. If your primary care office cannot remove them, you may return to your surgeon's office to have them removed at the instructed time.

If you have Steri-strips in place, they will fall off on their own in 1-3 weeks. You do not have to pull them off.

Follow your surgeon's recommendations regarding getting your wound wet. Most importantly, you should keep the surgical area clean and dry until it is completely healed, which could be up to 2-4 weeks after the sutures, staples or steri-strips are gone.

If there is drainage, redness or swelling around your wound, please call your surgeon.

Walking and exercise

Walking short distances as tolerated is recommended. It also prevents clots and muscle stiffness. Pace yourself and do not allow yourself to become overly tired. Start with short distances and gradually work yourself up to 30 minutes of walking daily.

Avoid lifting more than 15-20 pounds for six weeks. No heavy housework for four to six weeks. Avoid climbing stairs until your strength and balance have returned.

When you should call your surgeon

If you experience any of the following symptoms at home, please call your doctor immediately.

- Increased weakness or numbness of the face, arm or leg on one side of the body.
- Vision changes including loss of vision, sudden blurred vision or double vision.
- Loss of speech or difficulty talking or swallowing.
- Sudden, severe headache with no known cause.
- Increased sleepiness or confusion.
- Painful, frequent urination or unable to urinate.

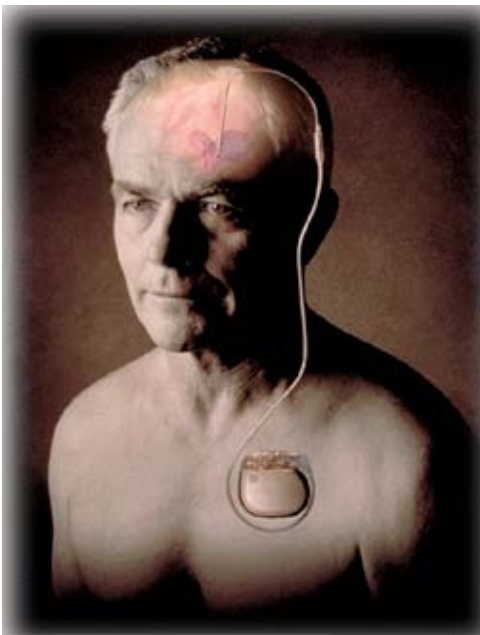
- Temperature greater than 100.5°.
- Bleeding from the surgical wound.
- Signs of infection (redness, swelling, draining wound).
- Leg calf pain or tenderness.

Important phone numbers to remember

Once you leave the hospital, you may have questions for any of the people who have cared for you. Here are some important numbers:

The Ohio State University Medical Center is (614) 293-8000. You can reach any extension from this number.

Between 8 AM and 5 pm Monday through Friday, you can call your surgeon's number. After hours, you will be given to an answering service to have the resident paged.



www.henryfordhealth.org

FREQUENTLY ASKED QUESTIONS

Q: Am I allowed to eat or drink the day my bone fiducials are placed?

A: YES. Local numbing medicine does not require you to stop eating or drinking before the procedure.

Q: Will my hair

A: Usually not. need to shave



be shaved when the bone fiducials are placed? Occasionally, your neurosurgery team will shave small parts of your hair.

Q: Can I get my hair in place?

A: YES

head wet/wash my hair with the bone fiducials

Q: How long will

A: The bone electrodes are placed.

the bone fiducials stay in my head?

fiducials will be removed at the time your

Q: Would both sides of the brain be done at once, or only one? The decision to place bilateral DBS depends on your symptoms and general health. If indicated and no major health problems are present usually both sides will be done at once.

Q: If I am a candidate for surgery, will I have to continue to take Parkinson drugs after DBS is placed?

A: Yes. However, you may be able to use less medication to control your symptoms.. Your neurologist will determine appropriate medications dosages and scheduling for you after your procedure.

Q: Why do I have to wait 4 weeks after surgery to have my device programmed?

A: Initially after surgery, there is swelling surrounding the lead, which may cause a temporary improvement in your symptoms. Programming needs to occur after the swelling has stopped to determine appropriate settings for your symptoms.

Q: Will surgery cure my Parkinson's disease? No. Surgery is not a permanent cure. Surgery manages the symptoms only. Unfortunately, it does not stop the disease progression.

Q: How will I know if the surgery was successful?

A: Your symptoms will decrease in severity or you will require less medication to be adequately controlled.

Q: Will I need to continue seeing the doctor who performed my surgery?

A: You will be asked to come back to your surgeon's office 6-weeks after your surgery

Q: Is it normal to feel pain for weeks after the procedure?

A: In order for your surgeon to remove parts of your spine, the layers of tissue and muscle must be cut. This will result in pain. Each patient rates their pain differently. Every effort will be made to lessen your pain. We cannot, however, promise that you will ever

be pain free. The main goals of surgery are to improve your function and keep your independence and provide stability. In many instances, your pre-surgery pain should improve, but will not completely go away.

Q: Will my neurosurgeon give me pain medications?

A: When you are discharged from the hospital, you will be given a prescription for pain medications and instructions for use based on your procedure, pain rating and hospitalization. In some cases this will be plenty to cover your post-operative pain. In some cases, it may not be. We encourage you to let us know if the pain is getting worse instead of better. If your pain persists beyond a reasonable recovery time, we will refer you to a pain specialist to manage your pain as we are not here to provide chronic pain medications. Some patients return to their primary care providers who manage their chronic pain issues.

Q: What precautions should be followed after surgery?

A: During the first six to eight weeks after surgery you should avoid lifting, bending, and twisting movements.

Q: How do I donate my own blood for my surgery? Can a family or friend donate blood for my surgery?

A: If you are planning to donate your blood for surgery or someone would like to donate blood for your surgery, contact the American Red Cross at the Columbus, Ohio office at 614-251-1451. They will be able to answer your questions regarding fees, time, preparation and scheduling. Keep in mind that they will not be able to do this if your surgery is within 1-3 days.

Q: When can I return to work?

A:

Q: What if surgery doesn't work? Can I have it again?

A: It is important that you keep realistic goals of the surgery and discuss them with your family and surgeon. We cannot guarantee a pain-free life. Recovery and success from surgery depends heavily on you! You should listen and follow recommendations such as exercise, practice good body mechanics, avoid behaviors that can affect healing, e.g. smoking, and know your physical limitations.

GLOSSARY OF TERMS

Ambulatory Surgery Unit: Area of the hospital dedicated to preparing patients for surgical procedures

Anesthesia Team: Health care professionals who specialize in pain management and putting patients to sleep during procedures and operations



Bone Fiducial: A small screw placed in the skull to help in mapping out structures of the brain.

Craniotomy: Procedure performed in the operating room where a portion of the skull is removed to gain access to the brain

Diagnostic Test: Information gathered to determine the cause of a problem

Dyskinesias: consist of involuntary writhing and twisting movements typically of the limbs. Usually first noted after years of levodopa treatment. These present during the periods when levodopa concentration is higher in the blood.

Lesioning: Destruction of targeted, abnormal brain tissue.

Neurologist: A medical doctor who specialized in problems of the brain and nervous system

Neurosurgeon: A medical doctor who specializes in operating on structures of the brain and spine

On/Off Phenomenon: A state in patient's of Parkinson's disease undergoing levodopa treatment in which the individuals exhibit a rapid fluctuation of between periods of almost normal function/diminished slowness and tremors("on" period).and severe rigidity and slowness ("off" periods).

Parkinson's disease: A disease characterized by loss of dopamine producing cells in the brain. This affects the motor systems of the brain causing: tremor, or trembling in hands, arms, legs, jaw, and face; rigidity, or stiffness of the limbs and trunk; bradykinesia, or slowness of movement; and postural instability, or impaired balance and coordination

Recurrent: An activity that continues to happen, or disappears and comes back again

Side Effects: Any unwanted result of taking a medication, such as rashes, fatigue, or headache

Surgical Intensive Care Unit: Area of the hospital dedicated to caring for patients requiring close monitoring after a surgical procedure.

ORGANIZATIONS AND WEBSITES OF INTEREST

American Parkinson Disease Association

135 Parkinson Avenue
Staten Island, NY 10305-1425
apda@apdaparkinson.org
<http://www.apdaparkinson.org>
Tel: 718-981-800; 800-223-2732
Calif: 800-908-2732
Fax: 718-981-4399

National Parkinson Foundation

1501 N.W. 9th Avenue
Bob Hope Road
Miami, FL 33136-1494
contact@parkinson.org
<http://www.parkinson.org>
Tel: 305-243-6666; 800-327-4545
Fax: 305-243-5595

Parkinson Alliance

P.O. Box 308
Kingston, NJ 08528-0308
admin@parkinsonalliance.org
<http://www.parkinsonalliance.org>
Tel: 609-688-0870; 800-579-8440
Fax: 609-688-0875

Michael J. Fox Foundation for Parkinson's Research

Grand Central Station

P.O. Box 4777
New York, NY 10163
<http://www.michaeljfox.org>
Tel: 212-509-0995

Parkinson's Action Network (PAN)

1025 Vermont Ave., NW
Suite 1120
Washington, DC 20005
info@parkinsonsaction.org
<http://www.parkinsonsaction.org>
Tel: 800-850-4726; 202-638-4101
Fax: 202-638-7257

Parkinson's Disease Foundation (PDF)

1359 Broadway
Suite 1509
New York, NY 10018
info@pdf.org
<http://www.pdf.org>
Tel: 212-923-4700; 800-457-6676
Fax: 212-923-4778

Parkinson's Institute

1170 Morse Avenue
Sunnyvale, CA 94089-1605
<http://www.theipi.org>
Tel: 408-734-2800; 800-786-2958
Fax: 408-734-8522

Parkinson's Resource Organization

74-090 El Paseo
Suite 102
Palm Desert, CA 92260-4135
info@parkinsonsresource.org
<http://www.parkinsonsresource.org>
Tel: 760-773-5628; 310-476-7030;
877-775-4111
Fax: 760-773-9803

National Institutes of Health Parkinson Information Page

Parkinson Disease – Hope Through Research
http://www.ninds.nih.gov/disorders/parkinsons_disease/detail_parkinsons_disease.htm

WE MOVE (Worldwide Education & Awareness for Movement Disorders)

204 West 84th Street
New York, NY 10024

wemove@wemove.org

<http://www.wemove.org>

Tel: 212-875-8312; 866-546-3136

Fax: 212-875-8389

Bachmann-Strauss Dystonia & Parkinson Foundation

Mt. Sinai Medical Center One Gustave L. Levy Place

P.O. Box 1490

New York, NY 10029

Bachmann.Strauss@mssm.edu

<http://www.dystonia-parkinsons.org>

Tel: 212-241-5614

Fax: 212-987-0662

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