

NEUROSCIENCES

Deep Brain Stimulation for Essential Tremor





Introduction

Welcome to OHSU's guide to deep brain stimulation surgery for patients with essential tremor. For some patients with essential tremor, DBS surgery offers life-changing relief.

DBS isn't for everyone, though. This guide explains the benefits and risks. It will also tell you how we learn if you are a good candidate.

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What is DBS?



DBS stands for deep brain stimulation. It comes from a small device that works like a pacemaker for the brain. Tiny leads, or electrodes, are placed in parts of your brain that control movement. The leads are connected by thin wires to a small device in the chest called an implanted pulse generator. The pulse generator sends steady, low-voltage electrical pulses to the leads. This stimulates those areas in your brain.

Researchers believe these pulses change the abnormal network of nerve signals in essential tremor. Or the pulses may change the brain chemicals that cause tremors and other symptoms.

DBS involves two surgeries. In the first surgery, your doctor puts in:

- **The leads:** Your doctor places the tiny leads, or electrodes, in parts of the brain that control movement.

In the second surgery, your doctor puts in:

- **The extensions:** Your doctor puts thin wires called extensions under the skin of the shoulder, neck and head.
- **The implanted pulse generator:** Doctors also call this an IPG or stimulator. Your doctor places it under the skin, usually below your collarbone, then connects it to the extension wires.

After surgery, your DBS team will adjust the stimulator settings. This is called programming. You may need several programming sessions to get the most relief. After that, you or your provider can use a programming device to adjust your stimulator or check the battery.

The leads go in one part of the brain: the thalamus.



Meet our clinical leaders

OHSU's DBS team is one of the most experienced in the nation and has received international recognition for its pioneering research and treatment.



Kim J. Burchiel, M.D., FACS

Dr. Burchiel is one of the most experienced DBS surgeons in the United States. In 1991, he was the first doctor in the U.S. to successfully treat a Parkinson's patient with DBS surgery. In 2011, he introduced asleep DBS, making the surgery faster, safer and more precise.



Delaram Safarpour, M.D.

Dr. Safarpour is a movement disorders specialist and the medical director of DBS program at OHSU, with a focus on improving patient care and satisfaction. She brings her experience in DBS candidate evaluations and programming from her training at University of Pennsylvania and Yale University.

Team approach

You will receive coordinated care from a team of specialists. These include experts in neurological surgery, neurology, physical therapy, speech therapy, neuropsychology and other areas. The team works together to give you the best treatment at every stage, from your first appointment to your care after surgery. Our specialists are experts in balance, gait, caring for older adults and other issues that are important for essential tremor. To learn more about our team members, visit www.ohsu.edu/dbs.

Research

OHSU doctors and researchers are continually improving treatment for movement disorders. We have published dozens of studies on DBS and hundreds on Parkinson's disease.

Screening

Our careful evaluation process makes sure you have DBS only if it is very likely to make a real difference. We offer other treatment options if DBS is not a good option for you.

Partnerships

Our nationally recognized OHSU Parkinson's Disease and Movement Disorders Program helps medical team members and scientists turn laboratory discoveries into treatments as quickly as possible.

"All I can say to anyone thinking about DBS is this: It's not a cure, but it's the next best thing. Everyone may not have equal results, but for me, the results have been nothing short of miraculous. I love it. I wear my DBS with pride."

— Thom, who had DBS surgery at OHSU

Our team

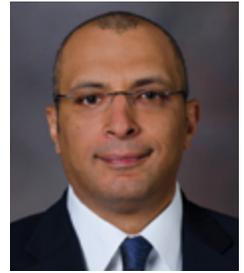
Neurological surgery



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Neurology



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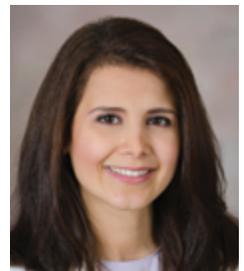
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You don't have to be awake for DBS

Asleep DBS

OHSU only performs asleep DBS. In asleep DBS, you have surgery under general anesthesia. You are not aware of any part of the procedure. During your surgery, the doctor uses high-resolution scans to precisely place the tiny electrodes in the brain. Asleep DBS is faster and safer.

Awake DBS

In awake DBS, you stay awake during surgery. You have medication to keep you comfortable, but you are aware of the procedure. This is because you must respond to questions and move to help the doctor place the DBS electrodes in the right part of your brain. Many patients are anxious about being awake during brain surgery.



Why choose OHSU?

Dr. Kim Burchiel of OHSU was the first doctor in the United States to perform DBS to treat Parkinson's disease. No other medical center has OHSU's experience with this procedure. Our team has excellent results and uses the most advanced technology available.

- **Experience:** OHSU is a leading center for DBS surgery. Since 1991, our team has done more than 2,000 procedures. Recently, a study ranked OHSU in the top four DBS providers for all teaching hospitals in the United States.
- **Excellence:** The Journal of Neurosurgery published a study of 60 OHSU patients who had asleep DBS. The study found this procedure was more precise than awake DBS and had very low risk. OHSU patients also have few complications from surgery. A recent study showed that fewer than four of every 100 DBS patients needed to return to the hospital within 30 days of having DBS. That puts OHSU among the nation's best.
- **Collaboration:** Your regular doctor remains part of your health care team. We help your doctor track your care online. We also make sure your doctor can contact your OHSU specialists at any time.
- **Convenience for patients outside Portland:** We treat patients from all over the world. We go out of our way to make appointments and testing as convenient as possible.
- **Nationally recognized program:** OHSU's Parkinson's Disease and Movement Disorders Program has been named a Center of Excellence by the Parkinson's Foundation. The center demonstrates OHSU's commitment to the most advanced patient care, research and education.



When should I consider DBS?

- Your propranolol, primidone or other medications do not work to control your tremor.
- You have severe side effects from your medications.
- Essential tremor causes problems with daily activities, such as eating.

Am I a candidate for DBS?

Deep brain stimulation can offer significant benefits for some patients, but it's not for everyone.

To have DBS, you must:

- Be able to have general anesthesia.
- Stop taking certain medications one to two weeks before surgery.

You are not a good candidate if:

- You or a caregiver cannot use a programmer to check the battery.
- You are not healthy enough for surgery.

Benefits and risks of DBS

DBS is renewable. The battery lasts one to four years, and your DBS team can replace it with a minor, low-risk, outpatient surgery.

Benefits

- DBS can improve your quality of life by reducing tremor. You can regain the ability to do daily activities such as getting dressed.
- DBS is reversible. Your DBS team can turn off your stimulator. The system can be left in place or removed.
- DBS is adjustable. Your team can change the settings to make it more effective or to reduce side effects.

Symptoms DBS helps

DBS mainly helps with action tremors of the leg and hands.

Symptoms DBS does not help

It is not as helpful with voice or head tremor.

Surgical risks

DBS is safe and effective. But, like all surgeries, it carries risks and possible side effects. Your DBS team will talk with you about the risks in detail.

Risks include:

- Infection.
- Bleeding in the brain.
- Stroke.
- Part of the DBS system breaking.
- The stimulator not working.



Your steps to DBS at OHSU

Your DBS journey for essential tremor has four steps at OHSU. If you live outside Portland, Oregon, we go out of our way to schedule these appointments as conveniently as possible. Bring a family member or caregiver to all your appointments.

Step 1 – Meet with a neurologist and neurological surgeon

You'll meet with an OHSU movement-disorder-trained neurologist about candidacy and then a neurological surgeon. They will determine if you could be a candidate for DBS. If you are not a good candidate for DBS, you will get recommendations for other treatments.



Step 2 – Presurgery appointments

- **MRI:** You will have a precise scan with OHSU’s powerful 3-Tesla MRI unit before surgery. The images will allow your neurosurgeon to begin planning where to place the leads during surgery.
 - This MRI is typically done without sedation. But please do not eat or drink before your appointment, in case you do need sedation or anesthesia. We will tell you how long to stop eating or drinking for, before the MRI.
 - If you do need sedation, you might need an extra day for this appointment.
 - Please bring a caregiver with you.
- **Neurological surgery:** You will sign a surgical consent form and can ask any questions. You and your family will also receive instructions for coming to the hospital on the day of surgery and for post-surgery care.
- **Presurgery physical examination:** This can often be done the day before surgery. We want to make sure you are healthy enough for surgery and anesthesia.



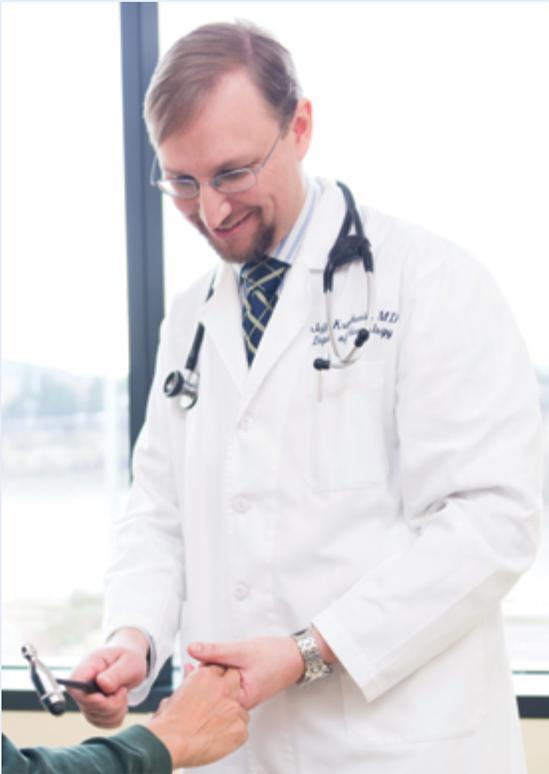
Step 3 – Surgery

Stage 1

- **Arrival and anesthesia:** You'll come to OHSU Hospital on the day of your surgery. The procedure will take two to three hours. In the operating suite, you'll be placed under general anesthesia. You will not be aware of anything during the procedure.
- **CT scan:** Your DBS team will position your head in a secure frame connected to a high-resolution CT scanner. The team will take a scan to match up with your high-resolution MRI images from before surgery. This will give your neurosurgeon the most accurate information possible for placing the leads.
- **Placing the leads:** Your neurosurgeon will place the leads, then take another CT scan to make sure they're in the right place. You will spend the night in OHSU Hospital and, in most cases, leave the next day.

Stage 2

- **Placing your stimulator:** Through a small incision above your ear, your neurosurgeon and his or her team will connect extension leads under the skin from the ends of the DBS leads to the implanted pulse generator, placed below your collarbone. This is done in a second surgery two to 10 days after the first one. This surgery takes about one hour. Your stimulator will not be programmed. You will leave OHSU the same day.



Step 4 – Programming and follow-up care

- **Programming your stimulator:** After your second surgery, a physician assistant, neurologist or both will program your stimulator. They will adjust the DBS settings with a small device called a programmer. You may need several programming sessions before you get the best symptom control. You will also receive a handheld programmer so you can check your stimulator’s status and battery.
- **Follow-up appointments:** Patients will be seen monthly until the programming settings have been optimized. After optimization you will return to seeing your doctor periodically for continued essential tremor care. You or a caregiver should have the battery checked at least every six months by a DBS provider. Your settings may be adjusted as your disease progresses or as needed.

It is best to have a caregiver with you at home as you heal from surgery.



Safe surgery

Make sure to tell your DBS team about all your medications and health conditions. You must stop taking some medications one to two weeks before surgery. Talk to your main doctor or cardiologist before stopping. Medications you need to stop before DBS surgery include:

- Warfarin (brand name: Coumadin)
- Plavix
- Apixaban (Eliquis)
- Dabigatran (Pradaxa)
- Rivaroxaban (Xarelto)
- Cilostazol (Pletal)
- Ibuprofen (one brand name is Motrin)
- Indomethacin (Indocin)
- Naproxen (brand names include Naprosyn and Aleve)
- Ketoprofen (Orudis)
- Celecoxib (Celebrex)
- Aspirin or medications that contain aspirin
- Mesalamine (Canasa, Apriso)

What to expect after DBS

Maximum symptom control: It usually takes a few months and several adjustments to your stimulator to see the full benefit of DBS.

The honeymoon phase: Occasionally symptoms can improve temporarily after surgery. Doctors call this the microlesion or honeymoon effect. It can last days or weeks. Do not lower or change your medication doses without talking to your neurologist. Not everyone experiences a honeymoon phase. Many patients report no change to symptoms and some report a temporary worsening of symptoms. Stay in touch with your neurologist to ensure your experience matches your expectations.

Cost and insurance

The cost of DBS is different for each person. It depends on your insurance and other factors. The DBS team will help you learn the details.

Does Medicare cover DBS? Read the Medicare standards for DBS or call the number on your Medicare card to learn more. You must still pay deductibles, coinsurance and copayments.

What about other health insurance? Non-Medicare health insurance often covers DBS if you get approval before surgery. Your doctor's office usually has to get authorization from your insurance company prior to surgery. This often means your doctor writes a letter saying why you are a good candidate.



Visiting Portland

Portland offers many lodging options, excellent restaurants, superior mass transit and a generally mild climate. OHSU's DBS sites are centrally located and accessible by car, bus, light rail and the Portland Aerial Tram. Some helpful websites:

- **Lodging and dining:** Travel Portland at www.travelportland.com.
- **Transit:** TriMet (bus and light rail) at www.trimet.org.
- **Tram:** The Portland Aerial Tram at www.gobytram.com offers easy access between our sites at the South Waterfront and Marquam Hill. Free courtesy tickets are available for patients and their loved ones.

Visiting OHSU

Getting here and parking

We provide DBS services at two locations, depending on the appointment. These are OHSU Hospital on Marquam Hill and the Center for Health & Healing at the nearby South Waterfront campus. For directions and parking information, please visit www.ohsu.edu/parking.

Information for caregivers

When you take care of someone with essential tremor, you may feel needed and important. You may find it difficult if your loved one needs less help after DBS. On the other hand, you might feel overwhelmed as a caregiver. You may be disappointed if DBS isn't a "miracle cure" and you still have significant caregiving responsibilities. The International Essential Tremor Foundation and the Family Caregiver Alliance offer tips for caregivers of essential tremor patients. These include:

- **Be prepared:** Learn what your loved one can and can't do alone. Understand your finances, including if and when to get power of attorney.
- **Find a support group:** The International Essential Tremor Foundation keeps a state-by-state list at www.essentialtremor.org/find-a-support-group.
- **Get help:** Seek help among family, neighbors, your religious congregation, senior centers and services such as Meals on Wheels. Consider hiring help with cooking, bathing and dressing. You can make a list of chores to share with family and friends who are willing to help for a few hours but aren't sure what you need.
- **Nurture your relationship:** Caregivers who have good relationships with the patient have better health and lower rates of depression.
- **Learn more:**
 - International Essential Tremor Foundation:
www.essentialtremor.org

Questions and answers about DBS

Is DBS a cure? No. DBS can make your quality of life much better but it does not cure essential tremor or keep it from getting worse over time.

Is DBS experimental? No. OHSU has been performing DBS since 1991. The procedure is FDA-approved for treating patients with essential tremor.

Will DBS make my essential tremor symptoms go away? If you're a good candidate for DBS, you can expect it to significantly improve your symptoms.

Will DBS keep me from doing certain activities? Talk to your neurologist about specific activities. After you recover from surgery, DBS should not keep you from regular activities such as swimming, bathing, sexual activity or sports.

Can I stop taking medication after DBS? Most patients can discontinue many of their essential tremor medications and reduce the amount of other medication they take under the guidance of their neurologist.

How long will the benefits of DBS last? This is different for everyone. For most patients, benefits last many years. A 2012 study published in *Stereotactic and Functional Neurosurgery* found that patients with essential tremor reported significant improvement regardless of whether they

had had surgery one year before or four years before.

I don't live near Portland, Oregon. Can I still consider OHSU? Absolutely. Our DBS team can work with patients from any area. We do everything we can to schedule multiple appointments on the same day to make it as convenient as possible.

Can I still see my regular neurologist? Yes. OHSU makes your regular health care provider a partner in your care through the entire DBS process.

Will I feel the electric pulses from my DBS? No; however, you will feel changes during programming and possibly when the device is turned on and off.

Can I control my DBS programming? Talk to your neurologist. Some patients have a controller that lets them adjust their DBS stimulator. The controller also lets them turn the stimulator on or off, or check the battery.

Will surgeons shave my head? Yes, shaving your head reduces the chance for infection.

Can I have DBS and a heart pacemaker? Yes. The devices need to be at least 10 inches apart. This might mean your DBS stimulator is placed in your right chest area instead of your left chest.

Where to learn more

At OHSU

To learn more about DBS at OHSU, visit www.ohsu.edu/dbs.

National

Find more at each site by entering DBS in the search field.

International Tremor Foundation:

www.essentialtremor.org;

find specifics on DBS at

www.essentialtremor.org/treatments/surgical-treatments

Tremor Action Network:

www.tremoraction.org

National Institute of Neurological Disorders and Stroke, essential tremor: Go to www.ninds.nih.gov and type “essential tremor” in the search field.

Medtronic, essential tremor information:

www.medtronicdbs.com/et

Abbott:

www.abbott.com

Boston Scientific:

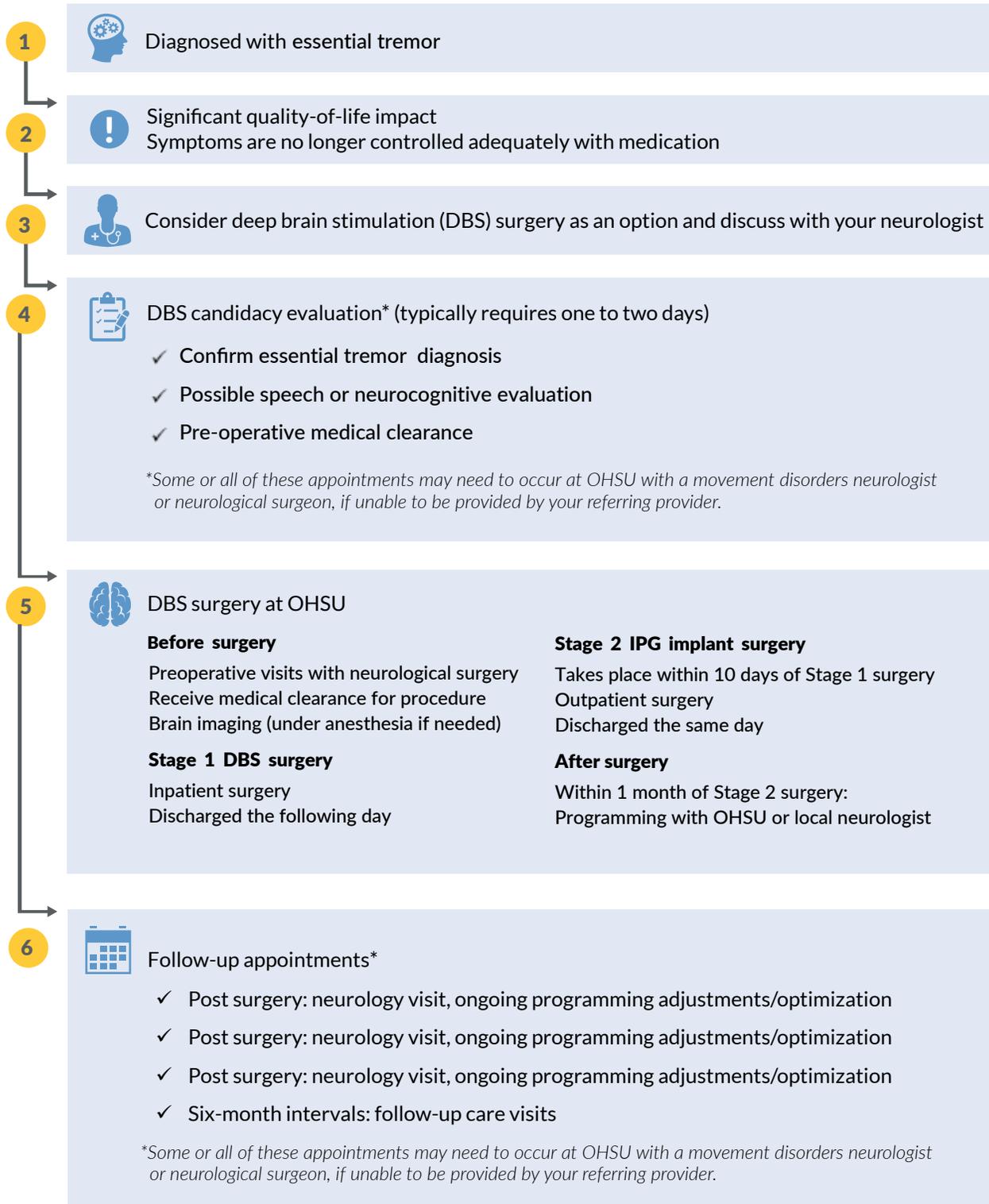
www.bostonscientific.com

The International Essential Tremor Foundation keeps a state-by-state list at

www.essentialtremor.org/find-a-support-group.

Essential tremor patient DBS surgery journey map

Each essential tremor patient is unique, as is their treatment plan. The guide below provides a general idea of the journey a typical DBS patient might experience.





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Mail code: BTE355
3181 S.W. Sam Jackson Park Road
Portland, OR 97239-3098

www.ohsu.edu/dbs

OHSU accepts most major health plans.

OHSU is an equal opportunity, affirmative action institution.

OHSU protects the privacy of its patients' and research participants' personal health information. If you would like a copy of the OHSU Notice of Privacy Practices, please call 503-494-8849.

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