

A Guide to Baclofen Pumps



Kennedy Krieger Institute

To our patients, families and caregivers,

We created this brochure to help our patients and their families and caregivers learn more about intrathecal baclofen pumps—what the pumps do, how they can help someone with spasticity, and what the process is to receive and maintain one. We've successfully managed baclofen pumps for patients since the late 1990s, and safety and communication are very important to us. We hope this brochure will help guide you in your journey. We value your input and appreciate your feedback. Please feel free to contact us with any questions or comments.

What Is Spasticity?

Spasticity is muscle tightness that makes movement—especially of the arms and legs—difficult or uncontrollable. It typically results from injury to a part of the central nervous system (i.e., to the brain or spinal cord) or from abnormalities in parts of the brain that control voluntary movements. Common conditions associated with spasticity include cerebral palsy, brain injury, stroke and spinal cord injury. Spasticity—which varies from mild stiffness to severe, painful, uncontrolled muscle spasms—can sometimes be very difficult to control and can interfere with activities of daily living.

What Can Treating Spasticity Do?

Treating spasticity:

- May promote comfort and improve ease of care.
- May improve gait, mobility and function.
- May decrease spasm frequency, pain and fatigue.
- May promote increased range of motion.
- Complements physical, occupational and speech therapies.
- May improve sleep.

Treating severe spasticity may require a combination of approaches. For some patients, intrathecal baclofen pump therapy may be a good option. Because a baclofen pump releases medication—baclofen—directly into the fluid of the spinal column, the baclofen does not enter the bloodstream. This avoids some of oral baclofen's potential side effects in the brain and gut, and avoids drug interactions for people with complex medication regimens to treat conditions such as seizures.

If your physician or therapist has recommended an evaluation for a baclofen pump, your next step is to make an appointment with our neurosurgeon and baclofen pump team to discuss the pump and determine if this is an appropriate treatment. We can plan for surgery when you are ready.



STEPS TO GETTING A BACLOFEN PUMP

1. Appointment with the neurosurgery team at Kennedy Krieger Institute.
2. Detailed preoperative physical therapy evaluation at Kennedy Krieger to assess muscle tone.
3. Test dose of intrathecal baclofen at Johns Hopkins (to be scheduled by the neurosurgeon at Johns Hopkins' Pediatric Neurosurgery Center).

If we determine your child is a good candidate for baclofen pump placement, you'll continue the process with the following steps:

4. Baclofen pump placement at Johns Hopkins (to be scheduled by the neurosurgery office at Johns Hopkins).
5. Follow-up appointments with the baclofen pump team at Kennedy Krieger for baclofen adjustments and refills.
6. Follow-up appointments with the physical therapy team at Kennedy Krieger to assess progress in physical therapy with the baclofen pump in place.

About the Intrathecal Baclofen Pump

An intrathecal baclofen pump is a device that delivers baclofen directly into the spinal canal. It is surgically placed under the skin of the abdominal region of the body. Attached to the pump is a tiny catheter that extends into the spinal canal. The catheter delivers baclofen to a specific area around the spinal cord—called the intrathecal space—precisely where baclofen is needed to help reduce spasticity and improve comfort and function.

The pump delivers baclofen continuously throughout the day and night. It can also be programmed to deliver different amounts of baclofen at different times. An external programmer uses telemetry to communicate with the pump and tell it how much baclofen to deliver.

Surgery to replace the pump will be required before expiration of the pump's battery, which lasts approximately seven years. We will help you track when this should be done. In most cases, this is a simpler surgery than the initial pump placement surgery: Only the pump is replaced; the catheter stays in place.

What to expect after baclofen pump placement surgery:

- **Relief of spasticity:** Once the pump has been implanted, the amount of baclofen released at any one time is slowly increased until an optimal therapeutic response to relieve spasticity is reached. Some patients may not notice an immediate improvement right after pump placement, because baclofen delivery always begins at a low dose, and is gradually increased.
- **Activity:** There are no major limitations on activities once the surgical incision has healed. Physical therapy may be resumed a few days after surgery. Patients are advised to avoid activities like riding horses or roller coasters for six weeks.
- **Pump refills:** The pump will need to be refilled at a Kennedy Krieger clinic every one to six months. The frequency of refills will depend on baclofen dosage, and on how fast the baclofen is used.

ALARMS

The pump has two notification alarms:

- A short sequence sounds once per hour when the amount of baclofen in the pump is low and a refill is due.
- A siren-like alarm sounds once every 10 minutes when the pump is empty. This is an emergency, and you must contact the baclofen pump team (the preferred response) or go to the Emergency Department of The Johns Hopkins Hospital for an urgent evaluation.

The baclofen pump team will review the alarms with you.

What are the possible side effects?

- Risks (which vary from patient to patient) associated with anesthesia during surgery.
- Low risk of bleeding.
- Risk of infection around the pump, catheter or surgical incision.
- Seroma (fluid collection) around the pump.
- Mild changes in bowel or bladder control (usually temporary).
- Overdose or underdose of baclofen.
- Catheter problems preventing the flow of baclofen.
- Pump failure or malfunction.

Can the pump give too much baclofen?

Overdosage is very rare, but can be caused by a programming error in drug concentration or delivery.

Know the signs and symptoms of too much intrathecal baclofen:

- Muscles that are too loose.
- Slow breathing.
- Drowsiness, sleepiness or confusion.
- Slurred speech.

Can the pump give too little baclofen?

Underdosage can occur if the catheter is not delivering enough baclofen. Once the dosage of intrathecal baclofen has begun, the drug should be given continuously. After a short time, the body will become dependent on baclofen. If, for any reason, there's a problem with baclofen delivery—which can occur if there's a problem with the pump or catheter, or if the pump becomes empty—acute or slow withdrawal can happen.

Know the signs and symptoms of withdrawal from baclofen:

- Sudden increase in muscle tone.
- High temperature.
- Itching without hives.
- Irritability.
- Change in mental status.
- Insomnia.

IMPORTANT!

Oral baclofen tablets can help reduce intrathecal baclofen withdrawal. Always carry tablets with you should underdosage occur. The baclofen pump team will explain how to respond if withdrawal is suspected.

Baclofen Test Dose

What does a test dose trial involve?

The test dose of intrathecal baclofen will be given in an operating suite at The Johns Hopkins Hospital by the neurosurgery team.

- Before the procedure, in the preoperative area of the operating suite, a Johns Hopkins physical therapist will likely evaluate spasticity and range of motion to document the baseline level of spasticity.
- The Johns Hopkins anesthesia team will administer general anesthesia in the operating room.
- The neurosurgery team will perform a lumbar puncture (i.e., spinal tap) to deliver a single dose of intrathecal baclofen into the space surrounding the spinal cord.

After the procedure, the patient will rest in a recovery room while the effects of the anesthesia wear off.

- The baclofen will begin to work within about two to three hours after the injection. The physical therapist will assess the baclofen's effect. If you'd like, family members may participate in the assessment process.
- If the trial is successful and we observe a beneficial response to the intrathecal baclofen, we will proceed with placement of the baclofen pump. Usually, but not always, this takes place the following day during the same hospital admission.

Important considerations:

- The trial uses only a single dose of baclofen and may cause significant reduction in muscle tone. This may be more or less dramatic than tone reduction from the pump, because pump dosing is continuous, and is adjusted specifically for each patient.
- Baclofen pump therapy is not suitable for everyone, and a trial will help determine if it is appropriate treatment. All factors influencing the decision to get a pump will be discussed before any decision is made.

Pump Placement Surgery

The surgery is usually performed the day after the trial and lasts about two hours. The procedure may last longer for patients who've previously had spinal fusion surgery.

Hospitalization will last from two to five days, depending on discomfort, constipation, feeding tolerance and other pre-existing medical conditions.

We recommend lying flat in bed as much as possible during the first night after surgery. This will help prevent headaches. Gradually sitting up and getting out of bed can begin on the second day after surgery.

Initially, the pump will be programmed to deliver intrathecal baclofen at a low dose. The baclofen pump team will increase the dosage during hospitalization, as needed. Many patients choose an inpatient rehabilitation stay following the surgery.

At Kennedy Krieger's inpatient rehabilitation hospital, patients receive frequent pump adjustments—from a few adjustments a week to daily adjustments, as needed—and multiple types of therapy. Most patients stay at the Institute's rehabilitation hospital for two to three weeks, depending on their rehabilitation goals.

After discharge to home, you will be scheduled for appointments every one to four weeks at a Kennedy Krieger clinic. The appointments will allow us to adjust the amount of baclofen received through the pump until optimal dosage and effect are achieved.

Postoperative Care

The surgery will require two incisions: one on the abdomen (four inches in length), and a smaller one (two inches long) over the lower spine. Steri-Strips will secure the incisions, and they usually fall off on their own. If they don't fall off, we can remove them two weeks after surgery. All sutures under the skin are absorbable.

In the days and weeks after surgery, there may be some swelling around the top and sides of the pump. This fluid build-up is a normal bodily reaction to the pump. An abdominal binder around the mid-section helps provide support and limit swelling. We typically recommend using a binder for six to eight weeks after surgery (longer for patients who are particularly thin).

If you notice any redness or drainage from the incisions, contact the baclofen pump team as soon as possible. After two weeks, if the incisions have healed, it is OK to swim or be immersed in water.

During a postoperative visit at a Kennedy Krieger clinic two to four weeks after surgery, we will check the incisions and ensure proper healing is taking place.

Activity:

- Avoid activities like roller-coaster rides and horseback riding for six weeks to avoid stress on the incisions and allow the body to heal with the catheter in place.
- Wheelchair adjustments may be necessary to fit the seat belt around the pump.
- Chest therapy vests and orthotic braces can be used starting about one week after surgery.

Medications:

- Acetaminophen may be taken for pain, every four to six hours, as needed.
- Continue oral baclofen until we instruct you to wean off of it. A schedule to gradually wean off of oral baclofen will be provided by the baclofen pump team.

Constipation:

- Constipation may temporarily worsen after any surgery, including surgery for baclofen pump placement. Some patients will note an improvement in their baseline constipation as their oral baclofen dosage decreases.
- Bowel movements should occur at least every two days for anyone. Patients with a preexisting bowel regimen devised with their primary care provider or gastrointestinal specialist should resume their presurgery bowel regimen after surgery.

Physical therapy:

- Periodic physical therapy evaluations will be scheduled to assess muscle tone and the effects of the baclofen pump. These evaluations are essential to ensure the pump is working properly, and to assist us in programming recommendations.



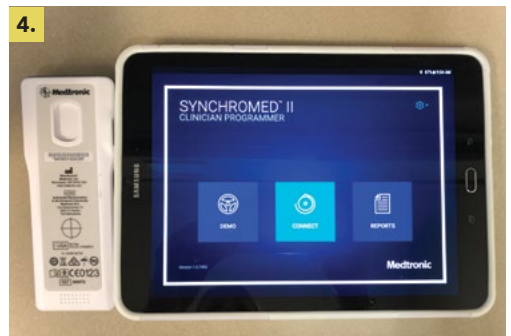
Pump Refills

The pump will need to be refilled every one to six months, depending on baclofen dosage. The baclofen pump team keeps track of how quickly the baclofen in each patient's pump is being used. When the time comes, we'll reach out to you to schedule an appointment to refill the pump. Refill appointments at Kennedy Krieger last approximately one hour.

If you need to change a refill visit, you must call us to reschedule. Refill appointments must not be missed.

The refill procedure:

1. One of the Kennedy Krieger baclofen pump team members will clean the area over and around the pump with a topical antiseptic solution. In some instances, we will use ultrasound guidance if there's any difficulty in locating the pump access site.
2. A cold spray will be applied to the skin over the pump to decrease the sensation from the small needle stick. Child life specialists will be available to provide education, coping techniques and psychosocial support.
3. We will insert a thin needle through the skin and into the port on the front of the pump. The old baclofen in the pump will be removed and replaced with new intrathecal baclofen.
4. Once the refill is complete, the handheld device will be used to program the pump. The team will also obtain the next refill alarm date from the pump.



REMEMBER!

1. Always carry a copy of the baclofen pump programming printout, or save a copy of it to your smartphone.
2. Be sure to let any healthcare providers, therapists, school nurses and teachers who work with your child know about the intrathecal baclofen pump. Our baclofen pump team can provide additional information to others who interact with your child.

When to Seek Help

Call the baclofen pump team immediately if:

- The pump is sounding an alarm.
- You feel the pump is delivering too much or not enough baclofen.

Report any of the following symptoms:

- Increased tightness of muscles, similar to before the pump was inserted.
- Floppiness.
- Unexplained fever (temperature higher than 101.5°F or 38.6°C).
- Itching without hives.
- Unexplained irritability.
- Drowsiness or severe insomnia.
- Nausea or vomiting.
- Headaches or dizziness.
- Redness, drainage or swelling at the incision site or around the pump.

Emergency and Routine Contacts

If you have a question or concern, or if you need to reschedule an appointment during normal business hours (Monday through Friday, 8:30 a.m. to 5 p.m.), call the baclofen pump team at Kennedy Krieger: **443-923-9141**

Outside of normal business hours, if you have a baclofen pump concern that cannot wait until the next business day, call the on-call physician at Kennedy Krieger: **443-923-9200**

The neurosurgeon's office at Johns Hopkins' Pediatric Neurosurgery Center: **410-614-3869**

The Johns Hopkins Hospital's after-hours answering service: **410-955-6070** (ask for the pediatric neurosurgeon on call)

For more information or questions: **BaclofenPump@KennedyKrieger.org**

Kennedy Krieger Institute recognizes and respects the rights of employees, trainees, and patients and students, and their families. At Kennedy Krieger, we ground our care, services, training and research in treating others with respect and civility. We respect the cultural identity of every person. Kennedy Krieger Institute does not discriminate against people based on, but not limited to, perceived or actual race, color, ethnicity, national origin, age, language spoken, accent, marital status, veteran or military status, immigration status, disability, religion, pregnancy status, sex, sexual orientation, or gender identity or expression. We strive for equitable care for all individuals for whom we provide services, training, education and research participation. We encourage employees, trainees, and patients and students, and their families, to become active partners in the services provided by asking questions, seeking resources and advocating for their needs. © 2021 Kennedy Krieger Institute 07/21

