

Intrathecal Baclofen (ITB) Plant Implant

A treatment for severe spasticity

Intrathecal Baclofen (ITB) therapy is used to manage severe spasticity. The goal of this therapy is to relax the muscles and improve your child's comfort and ability to move.

What is spasticity?

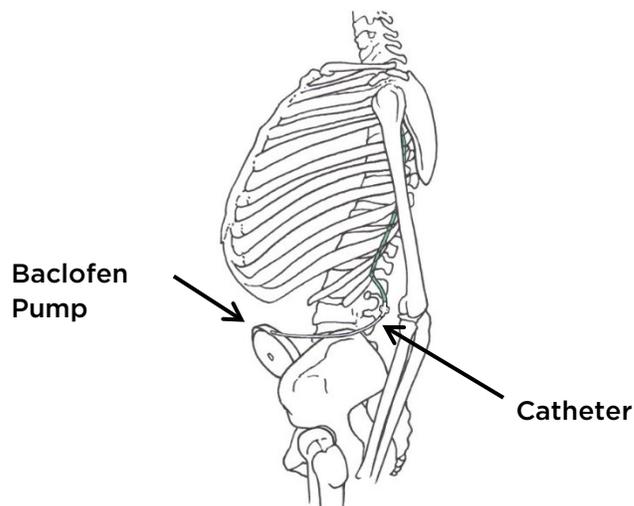
Spasticity is an increase in muscle tone that can be described as stiff or tight muscles. Spasticity is caused by a disruption in the messages between the brain and the muscles that tell the muscles to relax. It can be a result of illness or injury to the brain or spinal cord.

What is intrathecal Baclofen therapy?

It is a treatment option for severe spasticity (severely tight muscles), using a medicine called **baclofen** that is delivered through a small pump and catheter implanted under your child's skin. This system delivers the medicine into the fluid that surrounds the spinal cord, called the **intrathecal space**.

What is a baclofen pump?

It is a system that delivers medicine into the intrathecal space. This is done using a pump and catheter that are implanted under the skin. The pump, implanted in the lower belly (abdomen), is battery powered and stores and dispenses baclofen at the rate programmed by your child's doctor.



To Learn More

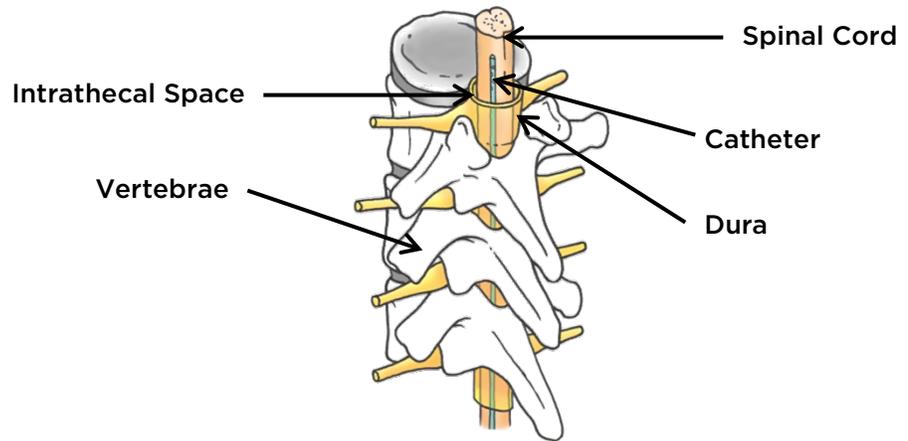
- Tone Management Program Manager
206-987-5917 | tone@seattlechildrens.org
- Neurosurgery Scheduling
206-987-2544, option 2
- Rehabilitation Medicine Scheduling
206-987-2114, option 2
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

Intrathecal Baclofen (ITB) Pump Implant

The catheter is a thin, flexible tube that is also placed under the skin and connected to the pump. It delivers the baclofen from the pump to the intrathecal space.



The pump is programmed by a handheld device that your child's doctor uses to communicate with the pump through skin and clothing.



Medical provider programming pump

How do I know if intrathecal baclofen (ITB) therapy is right for my child?

ITB therapy works well in treating severe spasticity caused by cerebral palsy or a brain or spinal cord injury or illness. We will do a careful evaluation of your child in our Surgical Tone Management Clinic to see if this therapy is right for them. This will include muscle testing by a physical therapist (called a “PT”), an occupational therapist (called an “OT”), and a Rehab doctor. A test dose may have been given to see how your child responds to the intrathecal baclofen before a pump implant is recommended.

When considering intrathecal baclofen therapy for your child, it is very important that your child is able to attend all follow up and pump refill appointments. If the pump runs out of baclofen, your child can be at risk for baclofen withdrawal. This is a potentially life-threatening event if untreated.

What happens before the surgery?

Your child will have a series of clinic appointments so we can get a detailed medical history, including recent illnesses, and learn about past experience with anesthesia. These appointments are scheduled within 30 days of your child’s procedure, usually all on the same day.

If your child has had a baclofen test dose procedure within 30 days of the baclofen pump implant surgery, they do not need to repeat the appointments below. If it has been longer than 30 days since their test dose procedure, the Pre-Anesthesia Surgical Services and Neurosurgery clinic visits will need to be repeated within 30 days of the implant surgery.

Pre-Anesthesia Surgical Services (PASS) Clinic

A nurse practitioner will meet with you and your child to make sure your child is healthy enough to receive anesthesia during the implant surgery. They will make sure your child does not have any health problems that could delay their procedure.

Neurosurgery Clinic

A nurse practitioner will meet with you and your child to review your child’s medical history and do a physical exam.

Radiology

The neurosurgeon may need additional X-rays or MRI scans of your child to use during the surgery. Your child may need anesthesia before an MRI if they are not able to lie still. We will talk with you about this before scheduling these appointments. To prepare, you can watch the videos *Getting an MRI While Awake* or *Getting an MRI with Anesthesia* available at seattlechildrens.org/clinics-programs/radiology.

Therapy

By the time your child is scheduled for an intrathecal baclofen pump implant, they will have already been seen by a physical and occupational therapist for their initial evaluation. Our therapists may see your child again before the procedure to gather specific measurements of their muscles and movement. The therapists may also videotape your child doing activities like transferring to and from a wheelchair.

What do I bring to these appointments?

Bring all of the items below that your child is currently using:

- Wheelchair
- Shorts to wear during the physical therapy visit
- Braces or splints for the foot or leg
- Any assistive devices your child uses to walk (arm crutches, walker)
- Name and phone number of your child's community physical therapists

Will my child need to stop taking oral baclofen or other medicines?

Your Rehabilitation doctor will talk to you before surgery about your child's medicine plan and any changes that may need to be made before and after surgery.

What happens during surgery?

Your child will be given general anesthesia, medicine that will make them sleep during the surgery. During the surgery, the neurosurgeon will make a 3 to 4 inch cut (incision) and form a pocket under the skin of your child's abdomen to hold the pump. Then the surgeon will make a second incision, about 2 inches long, on the back where one end of the catheter will be placed in the intrathecal space. The other end of the catheter is then tunneled under the skin from the back to the front and attached to the pump. Once the pump and catheter are placed, the incisions are closed, and the pump is programmed to start delivering baclofen. The surgery takes about 2 to 3 hours, including anesthesia and recovery.

How long will my child be in the hospital?

You can expect your child to be in the hospital for 3 to 5 days after surgery. During that time, the medical team will be watching for side effects including problems with constipation, or spinal fluid leakage. Your child's doctors and nurses will also watch for signs such as appetite and regular bowel movements that show your child is recovering well from surgery.

What should I expect after surgery?

Pain and Comfort

Your child's care team will refer to their medical history and experience with pain management before, during and after surgery. After the surgery, your child may feel some pain and discomfort in their back and abdomen. The care team will partner with you and your child to create a pain plan to help manage your child's discomfort with medicine if needed. You know your child best. No matter the level of your child's pain, believe they are hurting and respond right away.

Activity

During the first 24 hours after surgery, your child will be sleepy and recovering from the general anesthesia. Your child will remain in bed during that first day after surgery. After that, their activity will depend on what they can tolerate and how they respond to the intrathecal baclofen infusion. The care team will guide you and your child on safe movements and activities.

If your child uses a wheelchair, the medical team would like to see them sitting comfortably before going home. It may not be until 24 to 72 hours after surgery before your child is able to sit in a wheelchair. Your child's neurosurgeon or the neurosurgery nurse practitioners will help you decide when your child can do so. Sitting time should be built up slowly, starting with 1 to 2 hours at a time and increasing by about 30 to 60 minutes.

Your child may need to take a short break from their normal routine after they return home. This allows them to fully recover from the stress of the surgery and the hospital stay. Most children return to school 1 to 2 weeks after surgery. Use your judgment in deciding how long to keep your child out of school.

Baclofen Therapy

For some children, the effects of the intrathecal baclofen can be noticed right away (within the first 24 hours). For other children, it may take longer before the effects are seen (days to weeks). It may take several months before we find the dose of intrathecal baclofen that works best for your child. This is because the baclofen is highly concentrated, and the dose is increased by small amounts to avoid your child getting too much medicine. The dose being delivered by the pump may be increased daily while your child is in the hospital.

As the pump is turned up, other medicines such as oral baclofen may be decreased. Once your child returns home, the pump is adjusted in the outpatient Rehabilitation Medicine clinic, usually every 2 weeks until their optimal dose is reached.

What complications could occur?

Leaking of spinal fluid from the catheter site

Symptoms of a spinal fluid leak include back pain and headaches that go away when laying flat with head down.

Infection of the incision

If your child's incisions become infected, the pump and catheter will most likely need to be surgically removed in order to treat the infection. The care team will watch for signs and symptoms of infection before your child leaves the hospital.

Constipation

This can be treated through changes in diet or use of medicine as needed.

How do I prepare my child for a baclofen pump implant surgery?

For information and resources to prepare, visit seattlechildrens.org/patients-families/surgery/preparing-your-child/.

In addition, our Child Life specialists can work with you and your child to help relieve tension, express concerns and fears, and feel more in control about their hospital experience. Visit seattlechildrens.org/clinics-programs/child-life/ to learn more.

If you would like to meet with a Child Life specialist or speak with them over the phone, please ask someone on your child's medical team before the surgery.

What about lodging and transportation?

Parents and adult caregivers are welcome to stay in the room with your child during the night. Siblings and visitors may not stay overnight. If other family members need to stay close by, Guest Services can help you find housing. You can contact them at 206-987-9330 or 866-987-9330. We also have showers and laundry available.

For more information about planning your visit, transportation, and hospital services, visit seattlechildrens.org/visitors.

What do I do with my other children?

During clinic appointments

The Clinic Playroom is a place where brothers and sisters can play while patients and caregivers go to a clinic appointment. The playroom welcomes children ages 3 to 11 years old who are toilet-trained on a first-come, first-served basis. They may stay for up to 2 hours. Patients and younger children are welcome in the playroom when an adult is with them.

You can also visit the Mountain Play Park, our outside play area for all patients, families and visitors. Play is not supervised by staff and children must be with an adult family member. For more information about these services, visit seattlechildrens.org/visitors/campus/recreation.

After surgery

The Inpatient Playroom is for patients staying in the hospital and their siblings with an adult family member. It has toys, books, movies, crafts and games you can take to your child's room. It also has the outdoor play park and special activities in the playroom. When available, volunteers can come to your child's room to read and play with them during playroom hours.

What changes will my child's therapist need to make to accommodate the pump or the effects of the baclofen?

Changes to your child's therapy program or activities of daily living are based on how much spasticity/abnormal tone have impacted their functioning and care. Your child's therapist will need to re-evaluate your child's transfers and mobility skills in order to set new therapy goals. Getting feedback from both you and the people working with your child will help to guide the care team in making changes to your child's baclofen dose.

When will my child need to see the medical team for follow-up?

Medical follow-up

Your child will be seen by Neurosurgery, Rehabilitation Medicine and Physical and Occupational Therapy (OT/PT) after surgery. The purpose of this visit is to check their progress and make sure that they are getting the right therapy. Our schedulers will call you to make the following appointments:

After Surgery	2 to 3 weeks	3 months	6 months	1 year
Neurosurgery	X	X		
OT/PT			X	X
Rehabilitation	X	X	X	X

Pump Refills

Your child's pump will be refilled with baclofen in the Rehabilitation Medicine clinic. The appointment is scheduled for 1 hour, but the refill procedure only takes about 5 to 10 minutes.

We will offer your child numbing cream before the refill procedure to help lessen any pain and discomfort they may have. A Child Life specialist may also be available during your child's refill procedure to provide distraction and emotional support to your child.

During the refill appointment, your child's spasticity will be evaluated by a Rehabilitation provider to see if we need to adjust the dose. This will also be the time for you to bring up any other rehabilitation medical needs or concerns for your child that you may have. The refill appointments are scheduled 7 to 10 days before the pump is expected to run out of baclofen.

What if I have questions or concerns between appointments?

Any time you have concerns about your child's baclofen pump implant or their response to the medicine, the Rehabilitation Medicine team is available to answer questions or see your child in clinic as needed. Our providers are available nights, weekends, and holidays to provide medical support related to your child's intrathecal baclofen therapy.