Getting a Baclofen Pump

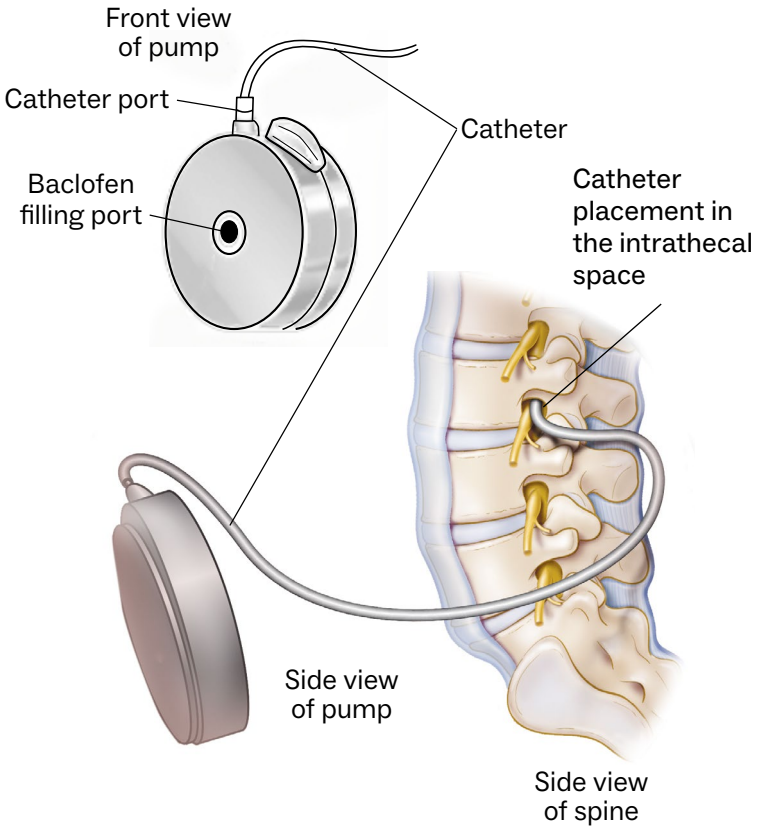
What is a baclofen pump?

An intrathecal [in-trah-THEE-kal] baclofen [BACK-low-fen] pump (or ITB) allows your child to receive a medicine that helps your child's tight (spastic) muscles relax.

What is spasticity?

Spasticity is when muscles tighten more than they should. This makes it hard to do things like move, talk, sit comfortably or walk. It usually happens when the brain or spinal cord do not develop normally or are hurt. Common conditions that cause spasticity are cerebral palsy, brain injuries, spinal cord injury and stroke. Spasticity can make it hard and sometimes impossible, to move and control muscles.

Intrathecal baclofen pump system

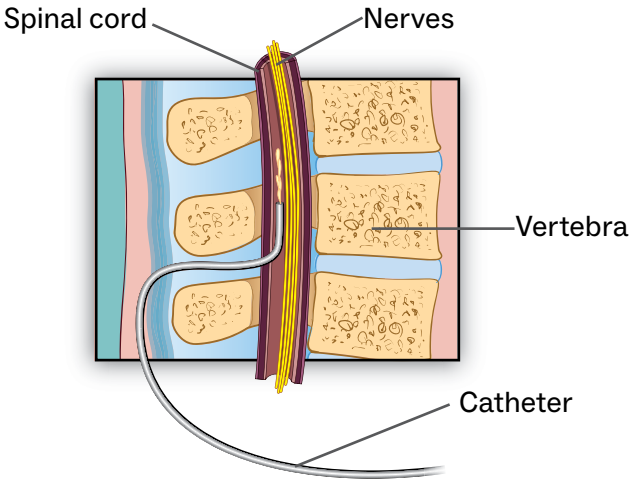


What does an ITB pump do?

An ITB pump is a medical device that connects to a small tube that pushes baclofen fluid into a small space around the spinal cord. This is called the intrathecal space. When baclofen reaches the intrathecal space, the nerves relax, and this makes the muscles relax. Your child will receive much smaller doses of baclofen through a pump than by taking baclofen by mouth or in a feeding tube.

Why does my child need a pump?

- An ITB pump may help children who do not have good results taking baclofen pills by mouth.
- An ITB pump can decrease spasticity and muscle tone. Delivering the baclofen near the spinal cord means your child will need less medicine. This smaller dose helps reduce side effects like sleepiness and constipation.
- Your child will get baclofen all day and night. Your child's healthcare providers can program the pump to give just the right amount of baclofen. They can also change the amount as your child's needs change.



Catheter placement in the intrathecal space

How do I know if a pump is right for my child and family?

The ITB pump requires regular doctor appointments to make sure it works correctly. You must learn how the pump works and watch it very carefully. To know if it's right for your child and family, ask yourself the following questions:

Will going to regular appointments at Primary Children's Hospital be a financial or time burden on your family?

- Does your family have reliable transportation to get to the hospital?
- Is your family planning to move?

If the pump is not right for you and your family, ask your child's healthcare provider how to manage your child's spasticity long-term.

What will the intrathecal baclofen pump do for my child?

The pump might be a good choice if your child is less stiff during the baclofen trial. You and the spasticity team will set goals that are within
reach for your child with a baclofen pump.

These goals may include:

- Easier care
- More comfort
- Self-care skills
- Seating and positioning
- Improved walking (a pump will not help a child walk if they could not before)
- Floor mobility
- Transfers
- Using a power wheelchair
- Motor skills
- Speech
- Sleep

What other treatments may help my child?

Other treatments may help the ITB pump be more effective. These include:

- Medications taken by mouth, like baclofen
- Botulinum and phenol injections
- Bracing
- Stretching
- Physical therapy
- Occupational therapy
- Orthopedic surgery
- Selective dorsal rhizotomy (SDR) surgery

Ask your child's healthcare provider about these therapies and interventions. They work together with the pump to help muscles relax, make them easier to move, and keep your child's joints flexible. They may help you decrease your child's spasticity but are not always needed.

What needs to happen for my child to get a baclofen pump?

Here are several exams and tests that can help determine if your child will do well with a baclofen pump. They might not need all of the tests.

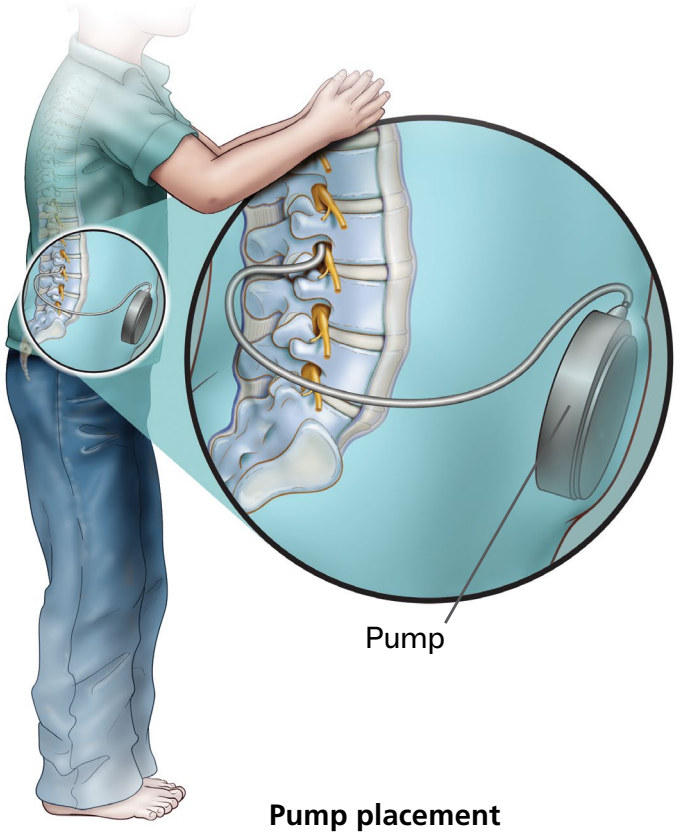
- **Spasticity evaluation**. A doctor and physical therapist look at your child's muscles and do measurements to see how much spasticity they have.
- **Baclofen trial.** Baclofen is placed in the fluid around your child's spinal cord to see how much their muscles relax and how strong your child is when the spasticity is gone.
- **Gait study.** This shows how well your child walks and how an SDR surgery might affect it.
- **Neurosurgeon visit.** The doctor does an exam to see if surgery is right for your child.

How do we prepare for baclofen pump surgery?

You will need to do the following things to prepare for surgery:

- Meet with a neurosurgeon.
- Keep giving all of your child's medications unless told not to.
- Help your child have a bowel movement the day before surgery. Your child will be moving less after surgery and the medicine that helps your child sleep during surgery can make it hard to poop (bowel movement). Intrathecal baclofen can also make it harder for their bowels to move waste out of the body. Ask your doctor if you need help.

The hospital will call you the day before surgery (or on the Friday before if surgery is on Monday). They will tell you how to be ready and when to come. They will call earlier if other tests are needed before surgery.



Pump placement

What happens during surgery?

- The neurosurgeon will put a small tube under your child's skin that tunnels along the side of the belly to the lower back into the intrathecal space.
- Then, they will put an ITB pump under the skin of your child's belly. The pump is about the size of a hockey puck.
- Your child will probably be in the hospital for 2 to 3 days. They usually don't need strong pain medicines after they go home.

What do we need to watch for after surgery?

- Watch for any signs of infection within the first few weeks after surgery. These include fever, swelling, redness, or drainage around the pump site or surgery site.
- Pain that gets worse instead of better.
- Spinal headache and CSF leak can happen after the surgery. This usually goes away by laying flat. Call neurosurgery if the headache doesn't go away after a few days.
- The incision might not heal and close. This is called wound dehiscence [deh-HIS-sense].

Call neurosurgery if your child has any of these complications from surgery.

How do I care for my child after surgery?

- If your child is taking anti-spasticity medicines by mouth, do not stop the medicines suddenly. Decrease the medicines slowly. Your rehabilitation doctor will help you with a plan for stopping the medicine. We will try to decrease these medicines as we increase how much baclofen the pump gives.
- You can give your child acetaminophen (Tylenol) and ibuprofen (Motrin) to help with pain.
- Keep the incision dry after surgery. At first, give your child a sponge bath. Your child can then shower. You will get more instructions at the hospital.
- Your child will wear an abdominal binder for 6 weeks after surgery. The binder protects the area where the pump is placed and helps keep it in place while the area heals. It also helps fluid from building up. You will get one in the hospital.
- Dress your child in loose clothing (especially around the pump and incision area).
- Teach your child to avoid twisting or bending at the waist. Discourage them from sleeping on their stomach, army crawling, sliding down stairs, or doing any movement that puts pressure on the stomach for at least 6 weeks.
- Your child may return to school and light activities a week after the pump is put in place. You can do this when you feel like your child is ready.
- Occasionally, your child may have worse constipation after they get the pump. The care team will give you information about preventing constipation at your first clinic follow-up.
- Your child may need more therapy as their ability to stand and walk changes.
- While in the hospital, you will receive a temporary medical device card for your child. The pump manufacturer (Medtronic) will send you a permanent pump identification card in the mail about 6 weeks later. Take this card with you on vacations and to the airport. It will help you get through security.

If your child has a medical emergency, tell the healthcare provider your child has an implanted baclofen pump.

Important numbers

Neurosurgery: Call for concerns about the incision or problems with the surgery.
801-662-5340

PM&R clinic: Call for concerns about spasticity, baclofen or spasticity medications or how the pump is working.

- **Office hours: 801-662-5888**
  (Monday-Friday, 8:00 am - 4:00 pm)
- **After hours or weekends: 801-662-1000.**
  Ask for the rehabilitation doctor on call.

Emergencies: Call 911 or go to the nearest emergency room.

Notes

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