

Let's Talk About...

Baclofen pump

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

What does an intrathecal baclofen pump do?

An ITB pump has a small tube that pushes baclofen 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 pills.

Why does my child need an intrathecal baclofen pump?

An ITB pump may help children who do not have good results taking baclofen pills by mouth. Intrathecal baclofen can decrease spasticity and muscle tone. Because the baclofen is delivered right to the spinal cord, your child needs a very small amount of medicine. This smaller dose helps reduce side effects like sleepiness and constipation.

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.

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

The ITB pump requires regular maintenance, like refills and dose changes, to make sure it works properly. You must know the pump well and watch it very carefully. Ask yourself the following questions to determine if it's right for your child and your family:

- 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 other treatments may help my child?

Other therapies may help the ITB pump be more effective:

- Stretching
- Occupational therapy
- Bracing
- Orthopedic surgery
- Physical therapy

Ask your child's healthcare provider about these therapies and interventions. They can help the pump work better but are not always needed.

What is an intrathecal baclofen trial?

An intrathecal baclofen trial is a way to see if a baclofen pump will help lessen your child's muscle tone. Your child will have an all-day appointment at Primary Children's Hospital in the rapid treatment unit (RTU). The baclofen pump trial begins at 7 AM and ends around 3 PM. You are welcome to stay in the procedure room to comfort your child.

Your child will receive an injection of baclofen, and a healthcare provider will measure their muscle tone before and after the injection. After the first measurement, your child will have numbing cream on their skin and then have a lumbar puncture (spinal tap).

A healthcare provider will put baclofen into the intrathecal space through the lumbar puncture needle. They will use a type of live x-ray called fluoroscopy (flurr-OSS-koh-pee) to make sure the needle and medicine are in the right place. After the injection, your child will lay flat for 4 hours in the RTU. The medicine works best after about 4 hours. It will then take about 4 more hours to wear off.

The spasticity team (physical therapist, baclofen pump nurse, and a rehabilitation doctor) will check your child's muscle tone carefully during this time. They may videotape your child's movements as well.

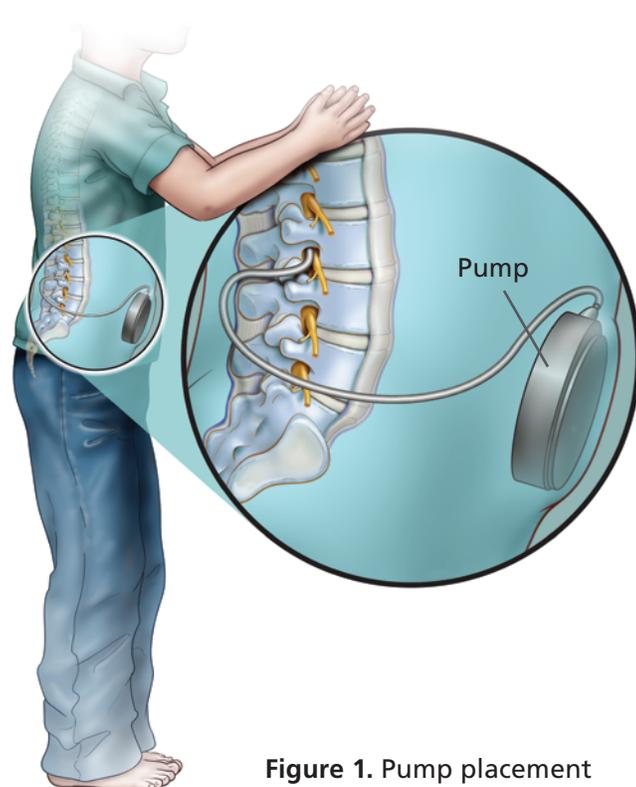


Figure 1. Pump placement

The risks of this procedure are small. Your child may get a headache from the lumbar puncture, and there is a slight risk of bleeding and infection.

What will the intrathecal baclofen pump do for my child?

If your child is less stiff during the baclofen trial, you and the spasticity team will set goals that your child can achieve with a baclofen pump.

These goals may include:

- More comfort
- Easier care
- Self-care skills
- Seating
- Positioning
- Floor mobility
- Transfers
- Using a power wheelchair
- Walking
- Motor skills
- Speech
- Sleep

The ITB pump may also help prevent deformities from getting worse. If the trial shows that an intrathecal baclofen pump will help your child, you will be referred to the neurosurgery department.

How will my child get an intrathecal baclofen pump?

The neurosurgeon will put an ITB pump under the skin of the belly during surgery (figure 1). The pump is about the size of a hockey puck. They will also 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 (figure 2). Your child will probably be in the hospital for 2–3 days.

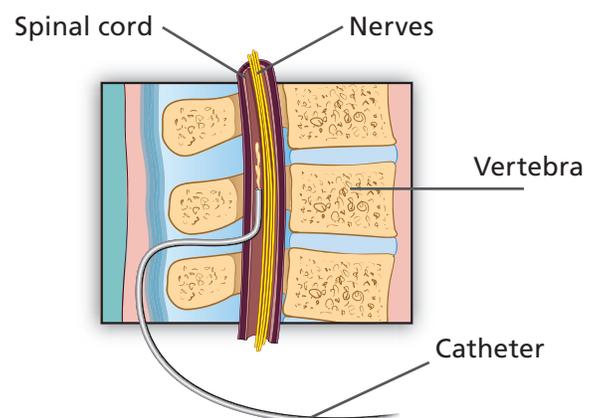


Figure 2. Catheter placement in the intrathecal space

What are the risks of an intrathecal baclofen pump?

Complications after the procedure include:

- Your child can get an infection within the first few weeks after surgery. Signs of infection include fever, swelling, redness, or drainage around the pump site or surgery site.
- Too much baclofen can cause headaches, drowsiness or nausea. Your child may be a little sleepy after the pump rate is increased. This is normal and usually gets better after the first week. If it does not get better, call your child's healthcare provider.
- Baclofen withdrawal can happen if the catheter gets kinked or broken. It can also happen if you miss a pump refill appointment. The signs of baclofen withdrawal are a sudden increase in muscle tone, agitation, and itching without a rash. Your child may also have a fever. If this happens, immediately give your child baclofen by mouth, as directed by your rehabilitation provider and then call your nurses.

How do I care for my child after surgery at home?

- Keep the incision dry for a week after surgery. At first, give your child a sponge bath. Your child can then shower and keep the incision dry by covering it with gauze and plastic wrap.
- Your child will wear an abdominal binder for six weeks after surgery. The binder protects the area where the pump is placed and helps keep it in place while the area heals.
- Dress your child in loose clothing (especially around the pump and incision area).
- Ask your child to avoid much twisting or bending at the waist. Discourage your child from sleeping on their stomach, army crawling, sliding down stairs, or any movement that puts pressure on the stomach.
- Your child may return to school and light activities a week after the pump is put in place.
- Your child may need more therapy as their ability to stand and walk changes.

- Occasionally, your child may have worse constipation after they get the pump. Healthcare providers will give you information about preventing constipation at your first clinic follow-up.
- If your child is taking anti-spasticity medicines by mouth, do not stop the medicines suddenly. Decrease the medicines slowly using the schedule from your child's rehabilitation doctor.

What happens after my child gets an intrathecal baclofen pump?

Having an ITB pump put in at Primary Children's means you commit to tell the hospital team about your child's progress and any issues that come up. The pump requires dose changes and regular refills. Here's what you need to know after your child receives an ITB pump:

- At first, your child will have frequent follow-up visits with the baclofen pump nurse to make dose changes. Initially, there are many appointments within the first 2–5 months, but your schedule may vary.
- Dose changes are made with a handheld computer that “talks” to the pump through the skin. At the first follow-up clinic visit after your child receives their pump, the baclofen nurses will help you schedule the dose change appointments. Visits are less frequent over time. Eventually, your child will need to come to the rehabilitation clinic only for pump refills, occasional dose adjustment, and yearly evaluation. The medical team is always available for questions.
- The baclofen pump has to be refilled every 2–6 months, depending on your child's dose. It is refilled by injecting the baclofen into the pump through the skin. You will receive a cream to numb your child's skin an hour before you come to the refill appointment. Music therapy, books, toys and other distractions can make the refill appointment less scary. Let the baclofen pump nurses know if you think your child would be comforted in other ways at the hospital.

