Intrathecal Baclofen Pump for Severe Spasticity and Dystonia

What is Spasticity and Dystonia?

- *Spasticity* is increased resistance to muscle movement. The faster the muscle is moved, the greater the stiffness.
- *Dystonia* is unintentional muscle tightening.
- Together *spasticity* and *dystonia* result in twisting and odd postures.
- In children, this is often described as going between being limp as a noodle and tight as a board.
- People with spinal cord injury may have severe *spasticity*.
- *Spasticity* and *dystonia* may be seen in people with cerebral palsy. It can also be seen in those with a brain injury.
- *Spasticity* and *dystonia* often cause problems with ease of movement, comfort, and care giving.

What is Intrathecal Baclofen?

- Baclofen is a medicine that eases muscle movement.
- Baclofen can be given by mouth.
- If the oral form isn’t helping enough, it can be given into the cerebral spinal fluid (CSF). “Intrathecal” refers to giving medicine directly into the CSF.
- If the spinal fluid route is used, a pump is needed. The pump is implanted inside the body. The pump allows the baclofen to be infused around the clock.

Who would be helped with a Baclofen Pump?

Your child may be helped by this pump if your child has:
- Spasticity or dystonia which affects the arms and legs.
- Problems with daily care, diaper changing, bathing, pain, or sleep.
- A body big enough to hold the pump.
- Enough strength in the neck and trunk.

How is my child assessed for the pump?

Each child is assessed by a team of doctors, nurses, and therapists. This takes place in the Spasticity and Movement Disorders Clinic at the Waisman Center. Parents can ask their child’s primary doctor for a referral to the center. Parents may call 608-263-7335 to schedule an appointment.
How is the intrathecal baclofen pump placed?

The system includes a pump, a tube (catheter) that goes into the spinal column, and a computer. The disc shaped pump is about 3 inches wide and 1 inch thick. It uses a lithium battery that will last 5-7 years.

![Diagram of baclofen pump](image)

During surgery, your child will lie on his side so that the back and stomach area are easy to reach. Through a small incision in the lower back, the baclofen pump tube is threaded into the spinal column. The other end of the tube is guided to the abdominal region. It is attached to the pump. The pump is placed through an incision in the mid to lower abdomen. It is set to give a fixed amount of baclofen over 24 hours. Placing the pump takes 1-2 hours.

What happens before surgery?

- Two weeks before surgery, your child will see the doctor for a physical exam, health review and lab tests.
- Stop aspirin and ibuprofen for two weeks before surgery. It is alright to use acetaminophen (Tylenol®) if needed.
- Wash your child’s hair, neck, chest, and stomach twice before surgery. Wash the night before and the morning of surgery. Use Dial® or another antibacterial soap on your child’s skin. Wash (do not scrub) for 2-3 minutes. Rinse well. Do not use lotions, powder or perfumes.
- Do not allow your child to eat anything or drink any juice with pulp or milk after midnight the night before surgery. No candy or chewing gum after midnight.
- It is alright to drink clear liquids until 4 hours before surgery.
- Do not allow your child to wear make-up, jewelry, or nail polish to surgery.

What happens after surgery?

After the pump is in place, patients go to the general care floor. Acetaminophen (Tylenol®) or ibuprofen (Motrin®) is given for pain. When your child is eating and drinking normally, the intravenous (IV) line may be removed. If there are no problems, your child may go home after 3 to 5 days.
At home, the incisions should be kept clean and dry. The pump is filled with baclofen at the time of surgery. It is programmed each day while in the hospital to make your child’s muscles looser. The pump has a built-in alarm for low battery and low medicine level. The alarm system will be reviewed with you before your child is released from the hospital.

**How should I care for the incision?**

Check the incisions twice a day until they are healed. If the incisions become infected, call your child’s doctor. The symptoms are:

- Redness, pain, or swelling of the skin at or near the site.
- Drainage from the incision.
- Fever greater than 101.5°F in the first three months after surgery.
- Irritability or feeling very sleepy.
- Feeling sick and needing to throw up.
- Headaches that keep coming back.

**Are there any activities my child should avoid?**

While the pump is in place your child should avoid:

- Extreme temperature and pressure changes.
- Saunas or hot tubs with temperatures over 102°F.
- Scuba diving under 2 atmospheres.
- Unpressurized aircraft.
- Bungee jumping.
- Sky diving.

The pump will need to be reprogrammed after MRI scans.

**When should I call?**

For signs of baclofen withdrawal or overdose.

**What is baclofen withdrawal?**

You should always have an up-to-date and filled prescription of oral baclofen on hand. If the pump does not work or the small tube becomes clogged or disconnected, your child may have symptoms of baclofen withdrawal. Give the oral baclofen. Call your child’s health care provider and make arrangements to be seen the same day. The symptoms are listed below.

- Severely increased spasticity or dystonia.
- Severe sweating.
- Severe itching without a rash.
- Fever.
- Seizures.
- Fast heart rate.
- Rapid breathing.
- Agitation.
- Irritability.
What is baclofen overdose?

If your child has too much baclofen, you may see the symptoms listed below. Call right away if you see these symptoms.

• Listless.
• Floppy.
• Very sleepy.
• Lightheaded or dizzy.
• Breathes slowly.

Will my child need routine follow-up?

Patients with baclofen pumps will need regular clinic follow-up for dose changes and for pump refills. It is vital to keep these appointments.

Phone Numbers

American Family Children’s Hospital Clinics: (608) 263-6420.

After hours, weekends and holidays, call the paging operator at (608) 262-0486. Ask for the neurosurgeon on call. Leave your name and phone number with the area code. The doctor will call you back.

If you live out of the area, call 1-800-323-8942