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 causes 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?
A baclofen pump may help if:
- Spasticity or dystonia which affects the arms and legs.
- Problems with daily care, pain, or sleep.
- The body is 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 Movements Disorders clinic at AFCH. Parents can ask their child’s primary doctor for a referral to the center. Parents may call 608-263-6420, option 3 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 last 7 years.

- Through a small incision in the back, the baclofen pump tube is threaded into the spinal column. The other end of the tube is guided to the abdominal region and attached to the pump.
- The pump is placed through an incision in the mid to lower abdomen.
- The pump is set to give a fixed amount of baclofen over 24 hours.
- Surgery takes about 2 hours.

What happens before surgery?
- You will need a physical exam, health review, and lab tests.
- Please stop aspirin and ibuprofen for two weeks before surgery. It is alright to use acetaminophen (Tylenol®) if needed.
- You will wash with Sage clothes as instructed.
- You will receive a phone call the day before surgery telling you when to stop eating and drinking.
- Do not wear make-up, jewelry, or nail polish to surgery.

What happens after surgery?
- There is mild pain involved with this. Pain relievers can be used to increase comfort.
- When you are eating and drinking normally, you will go home.
- Plan for a 3 to 5 day hospital stay.
- You will have a bandage covering the incisions. You will need to keep this dry and clean.
- You will have a clinic visit in 7-10 days. Your bandage and staples will be removed at this time.
- You should wait at least two weeks after surgery before getting any immunizations.
- The pump is filled with baclofen at the time of surgery. The pump will be adjusted as needed while in the hospital.
- Check the incisions twice a day until they are healed.
- Call right away if you notice:
  - 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.
  - Headaches that keep coming back.

Are there any activities that should be avoided?
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.
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.

Symptoms of baclofen withdrawal are:
- 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, option 3

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.