

# BACLOFEN PUMP THERAPY

Baclofen Pump Program at  
Boston Children's Hospital

PAGER:

617-355-6369 and ask to page #7867 (PUMP)



**Boston  
Children's  
Hospital**

Until every child is well

## Contents

What is spasticity? .....	3
What is baclofen? .....	3
The evaluation for getting a baclofen pump .....	4
Baclofen pump placement surgery .....	5
Baclofen pump FAQs .....	6
Baclofen refill procedure .....	7
Baclofen pump team .....	8

## What is spasticity?

Spasticity involves tight, stiff muscles that make it hard for your child to move or control their arms and legs and other parts of the body. It happens when there is an injury to a part of the **central nervous system** (the brain or spinal cord) that controls **voluntary** (on purpose) movements. Common conditions linked with spasticity include cerebral palsy, brain injury, stroke, multiple sclerosis and spinal cord injury. Spasticity can sometimes be very difficult to control and can get in the way of activities of daily living.

Treating spasticity may help:

- › Improve hygiene, activities of daily living and ease of care
- › Improve **gait** (how your child walks) and **mobility** (how your child moves)
- › Bring **spasms** (twitches and sudden, uncontrolled movements) down
- › Bring pain and fatigue levels down
- › Support bringing **tone** (muscle tightness) down and bringing up your child's range of movement
- › Support other treatments, like physical therapy, occupational therapy and speech therapy



*Patient with baclofen pump*

## What is baclofen?

Your care team may need to use a few different approaches together in treating your child's severe spasticity. One of the treatments used most often for this is **oral** (given by mouth) baclofen. Baclofen is a muscle relaxant. This treatment works for many people but some patients may need high doses to fully manage their spasticity. A higher dose may cause side effects, such as weakness, drowsiness and nausea. The higher dose still may not treat a child's spasticity as well as is needed. These patients may want to consider a baclofen pump.

### What are the possible side effects of baclofen?

Side effects of baclofen may include:

- › **Constipation** (not pooping enough)
- › **Urinary retention** (not peeing enough)
- › **Weakness**
- › **Nausea** (feeling like throwing up)

### What is a baclofen pump?

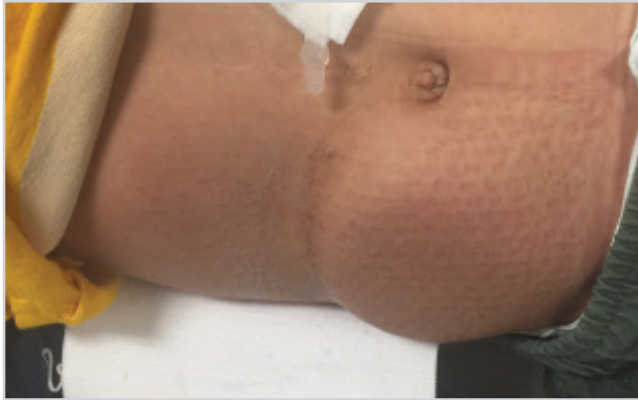
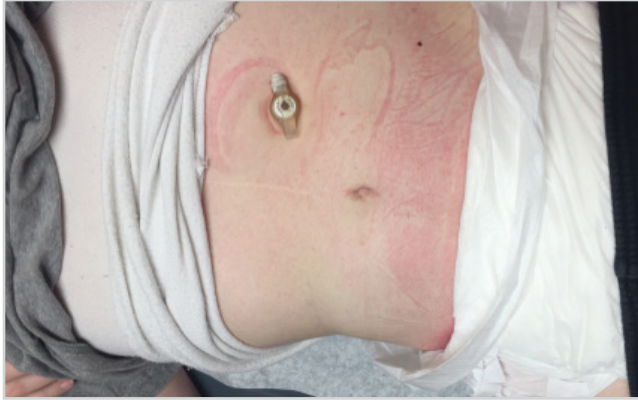
A baclofen pump is a small machine that is placed under the skin next to the **abdomen** (belly) near the hip bone. It is used to give **intrathecal** (given by injection into the spinal canal) baclofen from inside the body. The pump is connected to a **catheter** (tube) that helps send the medicine to a special part of the spinal cord (called the **intrathecal space**) where it will do the most good.

When baclofen is taken by mouth only a small amount of the medicine makes it all the way to this area.

### How does a baclofen pump work?

The pump sends baclofen steadily throughout the day to help with spasticity. It can also be programmed to send different amounts of baclofen at different times of the day, if needed. A very small computer is used to tell the pump how much medicine to give. The programmer uses **telemetry** (like radio waves) to send information to the pump.

Once the pump is implanted and the dose is raised step by step to a level that works for your child, you should be able to see a difference in your child's spasticity and comfort. There are no serious limits on what your child can do (like sports and other activities) once the surgery site is fully healed. Children can still do the things they did before the surgery.



Children with baclofen pumps

## The evaluation for getting a baclofen pump

If your doctor recommends a baclofen pump for your child, then you will meet with the baclofen pump nurse practitioners and learn about the pump to make sure it is the right choice for your child.

You and your child will meet with the neurosurgeon to talk more about the baclofen pump and make a plan for the surgery. The baclofen pump nurse practitioners will schedule this appointment.

A baclofen pump is not the right choice for every child. A trial may help you and your doctors decide if it's right for your child. The baclofen trial is optional. Patients who have had a spine fusion, or severe scoliosis, might not be candidates for a trial. You can discuss with your options your doctor.

### What does the baclofen trial involve?

1. A physical therapist will examine your child on the morning before the procedure to learn your child's baseline levels of spasticity.
2. Your child will be given a local or general anesthetic and an injection (called a **lumbar puncture**) of baclofen into the space surrounding the spinal cord. This is done in the operating room.
3. Your child should not feel any pain during the procedure because of the anesthetic. During the day, your child may have a headache. This can be a side effect of the lumbar puncture.
4. Your child will go to a recovery room after the procedure. Nurses will watch and care for your child while the effects of the anesthetic wear off. Side effects can include drowsiness, nausea and vomiting.
5. The baclofen will begin to work about 2–3 hours after the medicine is injected. At that time, a doctor and physical therapist will examine your child again to see if the baclofen has had any effect on your child's muscles.

If the trial is successful and your child responds well to the baclofen, then the team will go ahead with placement of the baclofen pump. If this is what you decide.

The trial is done with a single dose of baclofen and may have a serious effect on the tone (tension in the muscles) of your child's legs. Remember that this effect may not be the same as the effect from the pump. This is because the pump dosing will be continuous (always happening) and the amount will be set specially for your child.

## Baclofen pump placement surgery

If you and your child's doctors decide that a baclofen pump is the right choice, then the surgery is scheduled after meeting with your neurosurgeon. Surgery lasts about 2–3 hours. If your child has had a spine fusion, then the procedure may last a little longer.

Your child will have to stay lying down in a bed for 24 hours after the surgery to help prevent headaches. Your child can get out of bed after that time once they get used to sitting up again. Your child will stay in the hospital for 2–5 days after surgery, depending on how well they recover (pain, constipation, feeding, etc.).

The pump is programmed for a very low dose at first. The team will see your child on an outpatient basis every 1–2 weeks for small adjustments until the spasticity is improved.

### *Incisions and pump area*

After the surgery, your child will have Steri-Strips (white tape strips) across the incisions. These will fall off on their own. Keep them dry for the 2 weeks after surgery. You may take them off 2 weeks after surgery if they don't fall off. Your child may bathe, swim or get the incisions wet after 2 weeks if the incisions are healed.

For a few days to weeks after surgery, your child may have some swelling around the top and sides of the pump. This is from fluid and it is normal. An ACE wrap or abdominal binder around the belly helps add pressure to help with the swelling and make it less uncomfortable. Your child should wear the binder for 6–8 weeks after surgery.

If you notice any **drainage** (leaking fluid) from the incisions or any redness in the area you should contact the on-call Baclofen Pump Team through the hospital pager at #7867 (PUMP).

### **Surgery after-care**

#### *Activity*

Do not do any extreme bending, twisting or turning at the waist for 6 weeks. This will help keep the incision from being pulled and can help the catheter heal into place in your child's back. Other regular activities are fine.

Flying on an airplane is okay but be sure to let airport security know about the pump because it may set off security alarms.

#### *Medications*

You may give your child acetaminophen (Tylenol®) every 4–6 hours for pain if needed.

**Never** stop anti-spasticity medicines like baclofen or Dantrium suddenly. This can cause withdrawal symptoms and may lead to illness. These medicines need to be stopped slowly. Once your child has a good result from the pump (which may take a couple of months) we will make a plan to begin weaning the oral baclofen.

#### *Constipation*

Constipation will sometimes get worse due to intrathecal baclofen. Your child should have a **bowel movement** (poop) at least every 2–3 days. Keep your child on bowel medicines if they were being used before the surgery. Ask your child's doctor for help with this if needed.

#### *School*

Your child should be able to go back to school within a week after coming home from the hospital. The school nurse will not need to do anything with the pump but may need to move the binder to make sure it stays in the right position in the first couple of months after surgery.

#### *Coordination with other health care providers*

Be sure to let your child's other health care providers know that your child has a baclofen pump.

#### *Pump information*

Always carry the emergency card that will be mailed to you by Medtronic after the surgery. This card will give emergency personnel information about the pump.

### **Surgery follow-up appointments**

Appointments will be scheduled with the baclofen pump nurse practitioner every 1–2 weeks to adjust the dose of baclofen given through the pump until the best dose and effect are achieved. An appointment will be scheduled with your neurosurgeon about 4 weeks after surgery to check the incision and ensure proper healing.

## Baclofen pump FAQs

### What are some of the possible complications of a baclofen pump?

Possible complications include:

- › Bad reaction to anesthesia
- › Bleeding
- › Infection of the pump, catheter or wound (from surgery)
- › Mild changes in bladder control (these usually do not last very long)
- › Mild changes in sexual or bowel function
- › **Overdose** (too much) of baclofen
- › **Under-dose** (too little) of baclofen
- › Catheter kink (bent tubing) or clog which stops the flow of baclofen
- › Catheter break causing a baclofen leak
- › Catheter coming off of the pump, which keeps baclofen from reaching the spinal cord
- › Implant or pump failure or malfunction

### What stops the catheter from moving around?

The catheter is kept tightly in place with stitches. The catheter will move naturally with the spine as your child moves. The catheter will be long enough to allow for room for your child to grow.

### Can the catheter break or become clogged?

The catheter is made of very strong plastic and mesh. It is very rare for a catheter to break or clog but this can happen. If the catheter breaks your child will not get the full dose of baclofen. Your child will experience the symptoms of under-dosing. Scans and tests can be done to see if the catheter is broken. If the catheter breaks or clogs and you decide to go on with treatment then your child will need an operation to have a new catheter put in place.

### What is the battery life of a pump?

The battery in the pump lasts 7 years. Your child will have another surgery to replace the pump before the battery runs out. We will help keep track of when this will need to happen. In most cases it is a much simpler surgery the second time because your child's body is used to the pump being there already.

### Can my child get too much baclofen?

Overdose is rare. Children can get too much baclofen when a catheter is kinked and then becomes unkinked. This can also be caused by human error when programming the pump or because your child is sensitive to an increase in their dose of baclofen.

It is important to know the signs and symptoms of too much baclofen.

- › Call 617-355-6369, Pager #7867 if:
  - Your child's muscles are too loose
  - You child feels drowsy
- › Call 911 if
  - Your child has slow or irregular breathing
  - You cannot wake your child

### Can my child get too little baclofen?

Your child's body will become dependent on baclofen after a short time. If they suddenly stop getting baclofen for any reason this can make them very sick. This can happen because of a problem with the pump, a crack or break in the tubing or if the pump becomes empty.

### Signs that you child may be in withdrawal from baclofen:

- › Muscles are tighter than usual and not relaxing
- › High temperature
- › Itchy skin
- › **Irritability** (grumpiness)

If you are worried about withdrawal, page the baclofen pump pager at 617-355-5369, pager #7867 (PUMP).



If you think your child is getting too much or not enough baclofen, you must contact the baclofen team immediately.

Baclofen pump pager: 617-355-5369, pager #7867 (PUMP)

## Baclofen refill procedure

Your child's baclofen pump will need to be refilled every 2–6 months depending on the dose your child is receiving. On the front of the pump there is a silicon **port** (opening) in the middle. A long, thin needle is used to inject the baclofen through the silicon into this port.

The baclofen pump refill procedure is done in a clinic at Boston Children's or a Boston Children's satellite clinic. The entire visit will take 20-30 minutes. The procedure itself takes 5-10 minutes after getting positioned.

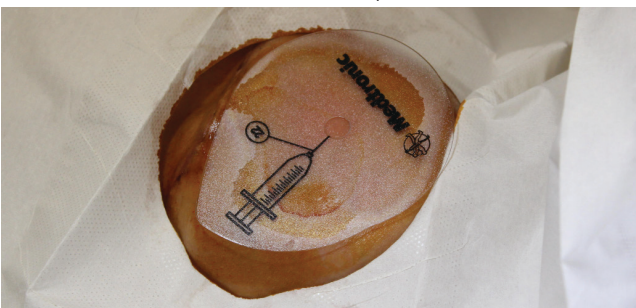
1. The skin over the pump will be numbed so your child will not feel the needle stick. The numbing cream is put on at home and should stay on for at least 60 minutes before the procedure starts.



2. The area over and around the pump will be cleaned with a topical antiseptic solution to make sure there are no germs in the area.



3. A special paper drape is placed over the abdomen with an open circle to show the pump. A small plastic template (sheet) is placed on the pump to help the doctor or nurse find the refill port.



4. A needle is inserted into the port of the pump. The old medicine in the pump is replaced with new medicine. The numbing cream used earlier will help keep your child from feeling any pain.



5. Once the refill is done, the pump is programmed so it shows that it has been filled with new medicine.



6. The nurse practitioner will schedule another refill appointment for your child before you leave.

We keep track of when your pump needs to be filled. If you need to change a refill visit you should contact your nurse practitioner right away. You must reschedule the visit when you call. If you miss a refill visit, your child could have withdrawal symptoms and may need to go to the hospital.

Page the Baclofen Pump Team if your child has any of the following symptoms:

- > Increased tightness of muscles
- > Floppiness
- > Fever (temperature higher than 101.5°F or 38.6°C)
- > Itchy skin all over
- > Unexplained irritability
- > Drowsiness (or you can't wake them)
- > Nausea
- > Vomiting
- > Headaches
- > Dizziness
- > Redness, swelling or drainage at the incision site
- > Swelling around the pump area

*You should also page us if you think the pump is beeping or if you believe your child is receiving too much or too little baclofen.*

---

Pager:

**617-355-6369 and ask to page #7867 (PUMP)**

## Baclofen pump team

**Kristin Buxton, MS, RN, CPNP**

Direct phone: 617-355-4713

**Ann Morgan, MS, RN, CPNP**

Direct phone: 617-355-9363

The Baclofen Pump Team at Boston Children's can be reached through the hospital operator at pager #7867 (PUMP) in case of emergency. A baclofen pump team member carries this pager 24 hours a day, 7 days a week.

For pump-related questions that can wait until the next day, you may contact the baclofen pump nurse practitioners at the numbers above during business hours.

Referrals to other families and patients with pumps are always available at your request.