Let's Talk About...

Baclofen pump

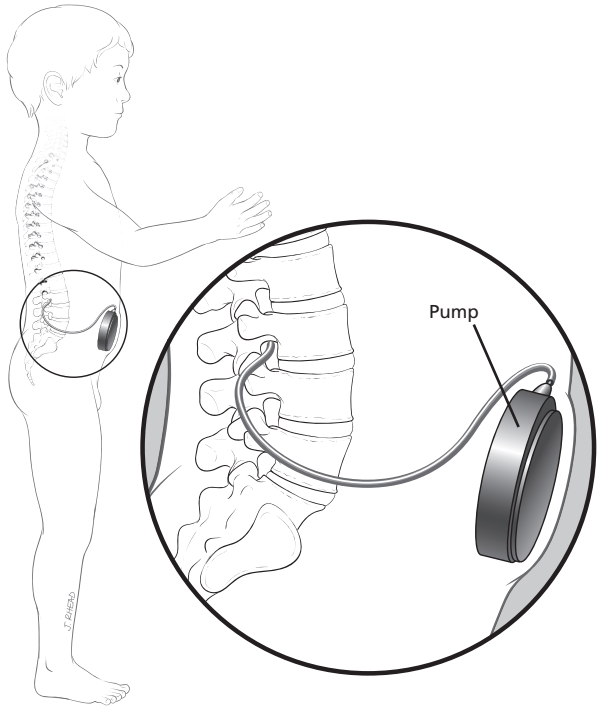


Figure 1. Pump placement

A Baclofen pump can help your child's spastic muscles relax.

Baclofen (BACK-low-fen) is a medicine that relaxes muscles. It does this by relaxing the nerves that go to the muscles. Baclofen can be taken by mouth (like a pill) or it can be given to your child with an intrathecal baclofen pump.

An **intrathecal** (in-trah-THEE-kal) baclofen pump is a pump put into the body during surgery. The pump has a small tube that pushes baclofen into the intrathecal space. The intrathecal space is a small space around the spinal cord. When baclofen is put in the intrathecal space, the nerves relax and that makes the muscles relax. Your child will receive much smaller doses than if he received the medicine by mouth.

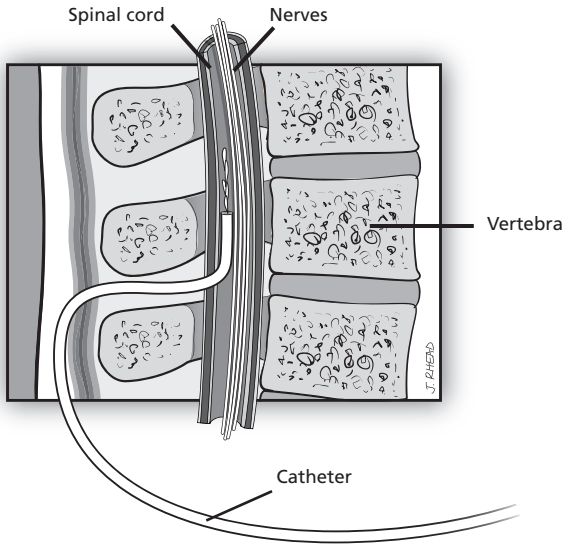
Why does my child need an intrathecal baclofen pump?

Intrathecal baclofen can decrease spasticity and muscle tone a lot. The nerves in the spinal cord cause the muscles to not relax. Because the baclofen is delivered right to the spinal cord, the child needs a very small amount of medicine. This smaller dose helps reduce side effects such as sleepiness and constipation. Your child's rehabilitation doctor or nurse can program the pump to give just the right amount of baclofen. They can also change the amount as your child's needs change. This may help children who do not have good results with baclofen taken by mouth.

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 receive this trial in the Rapid Treatment Unit (RTU) during an all-day appointment. The baclofen pump trials begin at 7 am and ends around 3 pm. Parents are welcome to be in the procedure room to provide as much

Figure 2. Catheter placement in the intrathecal space



comfort to their child as possible. Your child will receive an injection of baclofen and his muscle tone will be measured before and after the injection. After the first measurement, your child will have numbing cream on his skin and then have a lumbar puncture (spinal tap). During the lumbar puncture, baclofen is put into the intrathecal space through the lumbar puncture needle. The doctor uses a type of live X-Ray called **fluoroscopy** (flurr-OSS-koh-pee) to make sure the needle and medicine are in exactly the right place. After the injection your child will lay flat for four hours in the RTU. The medicine works best after about four hours, and then will take about four more hours to wear off. The spasticity team (physical therapist, occupational therapist, and a rehabilitation doctor) will check your child's muscle tone carefully during this time and may videotape his movements. 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 pump do for my child?

If your child is much less stiff during the baclofen trial, you and the spasticity team will set goals for your child that he can achieve with a baclofen pump. Goals may include improvement in comfort, ease of care, use of a hand, self-care skills, seating, positioning, floor mobility, transfers, use of a power wheelchair, walking, motor skills, speech, and sleep. The pump may also help prevent deformities from getting worse.

How will my child receive an intrathecal baclofen pump?

If the trial shows that an intrathecal baclofen pump will help your child, you will receive the contact information for the neurosurgery department. The neurosurgery department will schedule a time for surgery to put the pump in place. The pump is about the size of a hockey puck and is put under the skin of the belly during surgery (Figure 1) . The neurosurgeon puts 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 two or three days.

What are the risks to my child?

As with any procedure, there may be complications:

- Infection may happen within the first few weeks after surgery. Signs of infection are: fever, swelling, redness, or drainage around the pump site or the surgery site on your child's low back.
- If your child gets too much Baclofen it can make him drowsy, nauseated, or have a headache. Your child may be a little drowsy after the pump rate is increased. This is normal and usually gets better after the first week. If it does not get better, call the baclofen nurses.
- Baclofen withdrawal can happen if the catheter gets kinked or broken. It can also happen if you miss a pump refill appointment. Signs of baclofen withdrawal are sudden increase in 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 doctor, then call the baclofen nurses.
- You will learn about overdose and withdrawal at the baclofen trial and again during your first clinic follow-up.

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

- Keep the incision dry until the stitches are taken out. This is very important. At first, give your child a sponge bath. He can shower if he keeps the incision dry by covering it with gauze and plastic wrap.
- Your child will receive an abdominal binder after surgery. The binder protects the area where the pump is placed and helps keep the pump stay in place while the area heals. He must wear the binder for six weeks.
- Dress your child in loose clothing (especially around the pump and incision area).
- Encourage your child to avoid excessive twisting or bending at the waist. Discourage

your child from sleeping on his 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 his ability to stand and walk changes.
- Occasionally, a child gets worse constipation after he receives the pump. You will receive information about constipation prevention 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.

Deciding if the pump is right for your child and family

The baclofen pump is a medical device that requires regular maintenance (like refills and dose changes) to make sure it works properly. When deciding if the pump is right for your child it is important to understand you will have to be very committed, know the pump well and watch it very carefully.

Some issues to consider:

- 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?

What is my long-term commitment?

Having a pump put in at Primary Children's means you enter into a commitment with the hospital tea to keep them informed of your child's progress and any issues that come up. The pump requires dose changes and regular refills.

At first, your child will have frequent follow-up visits with the baclofen pump nurse to make dose changes. The average number of appointments is two per month for up to five months, but your schedule may vary. Dose changes are made with a hand-held computer that "talks" to the pump through the skin; no pokes! At the first follow-up clinic visit after your child receives the pump, the baclofen nurses will help you schedule 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 physician evaluation. The medical team is always available for questions.

The baclofen pump has to be refilled every two to six months, depending on your child's dose. It is refilled by injecting the baclophen 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 be used to make the refill appointment less scary. Let the baclofen nurses know if you think your child would benefit from further comfort measures.

Always know your child's pump alarm date! The pump has to be refilled about a week before the alarm date to prevent baclofen withdrawal. This is very important. If a child experiences baclofen withdrawal, this can lead to death. You will receive a blue baclofen pump information card at each clinic visit with any dose change, the new alarm date, and your next appointment.

The pump battery will last for six to seven years. The pump must be replaced before the battery runs out. This requires another surgery to replace the pump. If the catheter is working well, it does not need to be changed. The baclofen nurses will let you know when it is time to start thinking about battery replacement.

Are there other interventions that may help my child?

Along with the pump, other therapies may help the pump be more effective. More stretching, bracing, physical therapy, occupational therapy, or orthopedic surgery may help increase the effect of the baclofen pump. Speak to your doctor about

these therapies and interventions. These therapies and interventions can add to the benefit of the pump, but are not always needed.

If the pump is not right for you and your family, talk to your rehab physician about what you can do to manage your child's spasticity long-term.

Emergency information

You will receive two cards about the pump. If your child has a medical emergency outside of Primary Children's Hospital, give these two cards to the healthcare providers. Before any medical treatments, notify the treating healthcare provider that your child has an implanted baclofen pump and give them these two cards:

1. A pump identification card: you will receive a temporary card when your child is discharged from the hospital . The pump manufacturer (the Medtronic company) will send you a permanent pump identification card in the mail about six weeks after your child goes home after surgery.
2. A red emergency card with information about the pump: You will receive this at your first clinic follow-up.

Who should I call in an emergency or if I have questions?

- If your child has an emergency during regular business hours, please call Rehabilitation at 801.662.4949 and ask to speak to the Intrathecal Baclofen Pump Nurse.
- If your child has an emergency after regular business hours, call the Primary Children's Hospital operator at 801.662.1000 and ask the operator to page the Rehabilitation resident physician on call.
- If you have non-emergency questions, call the Primary Children's Hospital Rehabilitation Medicine Intrathecal Baclofen Pump Nurse line at 801.662.4949.

© 2014 Intermountain Healthcare, Primary Children's Hospital. All of the information contained in the ***Let's Talk About . . .*** series is for educational purposes only. This educational information is not a substitute for medical advice or for care from a physician or other health care professional. If you have questions about your child's health, contact your health care provider.

Pediatric Education Services, 801.662.3500 | Rev. 06/14, LTA520408232 | *Available in Spanish*