

Why does my child need a test dose of baclofen?

The baclofen test dose helps the doctor decide if an intrathecal baclofen pump might help your child. If your child's muscles become less stiff after the test dose, they may be able to get the pump.

What will the test dose be like?

- The test dose may be done in Radiology or in a procedure room. This depends on your child's needs and their doctor's preference.
- Your child may or may not need to stay overnight in the hospital. This also depends on your child's needs and their doctor's preference.
- For the test dose, a member of your child's care team will:
 - Put numbing cream on your child's back. This can help decrease pain where the needle goes into the skin.
 - Use a small syringe and needle to give a small dose of baclofen right into your child's spinal fluid. The fluid is in a space around the spinal cord in your child's lower back.
 - Remove the needle and put on a bandage.
 - Check your child's vital signs (heart rate, blood pressure, breathing and oxygen level).

What happens after the test dose?

To help keep your child safe after the test:

- Make sure they stay in bed until a member of the care team checks on them.
- Keep the bed siderails up. Ask the care team for help if you need to get your child out of bed.

The doctor or therapist will check your child's muscles for stiffness (spasticity).

- Your child may have trouble standing or walking because their muscles are so loose.
- Your child's muscles may loosen only a little, or they may relax so much that they cannot use them. This looseness is temporary.
- Your child's muscle stiffness will return in about 6 to 8 hours to the same level that it was before the test dose.

Your child may have 1 or more of these temporary symptoms from the test dose:

- Nausea or vomiting (throwing up)
- Drowsiness
- Loose muscles
- Headaches
- Dizziness

Let your child's nurse know **<u>right away</u>** if your child has any of these symptoms.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

When do I get the results of the test dose?

- The test dose is a screening test only. It will help to show if the medicine might help your child by decreasing muscle stiffness and spasms.
- The doctor may be able to tell you before you go home if the medicine might help your child.
- Some children do not respond to the first test dose. The doctor may give a second test dose using a higher dose on another day.

When should I call the doctor?

After you go home, call the doctor if your child has:

- Nausea or vomiting (throwing up)
- Redness, swelling, pus, drainage or bad smell at the test dose site
- A fever over 101°F that is not helped by acetaminophen (Tylenol or less costly store brand)
- Problems staying awake
- New rash or itching
- Severe (very bad) headache

What do I need to know if my child gets an intrathecal baclofen pump?

- Most often, the baclofen pump gets refilled during a clinic visit.
- To make sure the pump works as well as possible and to help prevent problems, you MUST:
 - Know your child's next pump refill date.
 - Bring your child to their follow-up visits.
- You MUST know the symptoms of too much baclofen (overdose) and too little baclofen (underdose). Both of these can cause serious problems and make your child very sick.
- You MUST take action and get medical help **<u>right away</u>** if you see any of these symptoms.

Symptoms of too much baclofen (overdose):

- Muscle weakness
- Being very sleepy and having problems staying awake
- Feeling dizzy
- Feeling lightheaded
- Seizures
- Trouble breathing
- Coma

Symptoms of too little baclofen (underdose):

- New rash or itching without a rash
- Increased muscle stiffness and tightness that gets worse

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

- Fever over 101°F
- Altered mental status (such as being agitated, confused, less alert or having slow responses)

Call your child's doctor right away or go to the nearest emergency department if your child has any of symptoms listed above.

- Take the Emergency Card and Implanted Device Card with you.
- Tell the staff that your child has an intrathecal pump as soon as you get there.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.