

## What Else Should I Think About?

Deciding whether to try intrathecal baclofen therapy may not be easy for you and your child. There are a few other things you should know before you proceed:

- The pump battery lasts 5 to 7 years, and the pump will have to be surgically replaced.
- You **must** keep all refill appointments as scheduled. Children may experience **serious** side effects if they go without their proper dosage.
- Currently the only place to have the pump refilled is at Sunny Hill.
- Your child can enjoy normal activity, but must be careful to avoid direct blows to the pump area.
- Your child is able to swim and travel by plane.
- While X-rays, CT scans or ultrasounds are safe, special precautions are required for MRIs.
- Your child needs to wear Medic-Alert identification at all times.
- Caregivers need to be aware of the pump and of signs and symptoms of potential problems.

Intrathecal baclofen therapy requires a considerable commitment from both you and your child. More information, and further consultation will be provided to you before you make your decision.



## About Sunny Hill

Sunny Hill Health Centre for Children is a provincial facility offering specialized services to children with disabilities, their families and communities throughout British Columbia. Using a family-centred approach, Sunny Hill helps promote the healthy development of children and youth by supporting families and community service providers in their efforts. It is also a resource for educational services and information about disabilities. Services are delivered close to home in a child's community, or on site at Sunny Hill, located in Vancouver.

## How To Contact Us

### Sunny Hill Health Centre For Children

Intrathecal Baclofen Clinic

3644 Slocan Street, Vancouver, BC V5M 3E8

Tone Management Nurse Clinician

Phone: (604) 453-8348

Fax: (604) 453-8301

[www.bcchildrens.ca](http://www.bcchildrens.ca)

*Promoting Better Health for Children with Disabilities through Clinical Services, Education and Research*



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## About Intrathecal Baclofen Therapy

Intrathecal Baclofen (ITB) is one of the treatments for tone management in adults and children. Baclofen is a drug that has been proven to be effective in controlling high tone by slowing down messages in the spinal cord that cause muscles to tighten up.

## What Are The Benefits For My Child?

Studies show that ITB can help selected children be more comfortable, be more independent and improve the use of their arms and legs. Even if your child is not able to care for him/herself, you and other caregivers may notice ease in care such as bathing, transfers and toileting.

## What Is A Baclofen Pump And How Does It Work?

Intrathecal baclofen therapy involves the use of a battery-powered, computer programmable pump that is surgically implanted and delivers doses of baclofen directly to your child's spine. The pump is a small disc about the size and weight of a hockey puck. It is implanted in your child's abdomen, about an inch below the surface of the skin. This will create a small bulge, but it's easily hidden by clothing. It is connected to a flexible tube, or catheter, that is placed in the intrathecal space, or fluid sack, that surrounds the spinal cord.



The pump is designed to deliver a prescribed amount of medicine to your child directly into the intrathecal space which then 'bathes' the spinal cord in the medicine.



The pump is refilled by inserting a small needle attached to a syringe through the skin. Numbing cream is put over the area to make sure your child is comfortable. Refills need to be done every 6 weeks to every 6 months depending on how much medicine your child needs. The refill takes about 30 minutes and is done by our clinic nurse or doctor.

The doctor or nurse tells the pump what to do by using a programmer (see picture insert), which can send and receive messages to and from the pump. The programmer lets the nurse and doctor change the amount and timing of the baclofen to make your child most comfortable with least amount of side effects.

## How Is The Pump Implanted?

Before the pump is put into your child, the doctors will make sure this is the right treatment by giving a test dose of the intrathecal baclofen. You and your child will spend 2-3 days at Sunny Hill for the test.

If you and the team decide the test is successful, the neurosurgeon will implant the pump during day surgery at BC Children's Hospital. Your child will stay at Sunny Hill for several days after the surgery to monitor his/her reaction, and start to find the right dose of baclofen.

## What Are The Risks?

Principally there are two main categories of complications. They are rare, but can occur, and are serious. They include:

1. Complications with the surgery include anesthesia problems, infection at implant site or of the spinal fluid. There can also be a fluid buildup around the pump area.
2. Complications that can occur any time after the implant. these include the risk of infection at the pump site or in the spinal fluid and potential problems with the catheter or pump that can mean too much or not enough medicine is given to your child. These problems will require surgical repair or replacement.

