Background

Intrathecal baclofen therapy (ITB) uses a surgically implanted medical device called a baclofen pump to deliver intrathecal baclofen and reduce symptoms of spasticity and dystonia. Muscles that involuntarily contract, become stiff or spasm can cause pain and make it difficult to move, function and perform activities of daily living. Such movement disorders can occur in conditions affecting the brain or the spinal cord including cerebral palsy, spinal cord injury, brain injury or stroke.

Baclofen produces muscle relaxant effects of the central nervous system and is used to treat muscle spasticity. Instead of taking oral baclofen medication everyday by mouth, a baclofen pump infuses intrathecal baclofen directly into the spinal fluid. This form of treatment delivers the medication directly to the site using a smaller dose and eliminating side effects associated with oral medication administration (e.g., upset stomach, constipation, urinary retention, headaches, sleepiness). This alternative to oral medication also helps eliminate potential drug interactions for people using multiple medications to treat complex conditions.

The ITB device consists of a pump about the size a hockey puck implanted under the skin, usually in the lower abdomen. A catheter is threaded from the pump to the spinal canal. Liquid baclofen is instilled in a reservoir port on the front of the pump and refilled as needed by the healthcare provider using a small needle. Depending on the specific medication dose and delivery rate for the child, most medications will last 1-6 months before requiring a refill. The device is operated by a lithium battery and will last approximately 4-7 years before it requires replacement.

The implanted device has specific notification alarms that will sound if the device has a problem, needs to be replaced, or requires a medication refill. The tone of the alarm varies based on the urgency of the problem and can be accessed via the device website (e.g., a short sequence sounds once per hour indicating the baclofen pump is running low, a siren-like alarm sounds once every 10 minutes indicating the pump is empty).

Adverse events like baclofen overdosage or underdosage can result from mechanical device problems such as internal component failure, empty medication reservoir, pump migration or flipping, or programming error. Other rare but serious complications can occur if the catheter migrates from its original location or if it becomes bent, kinked, or occluded. Overdosage is rare but can occur. When too much intrathecal baclofen is administered via the pump, an individual may have loose muscles or floppiness and complain of drowsiness or confusion. Slowed speech, slurring, and decreased respiratory rate can occur.

After three months, an individual becomes dependent on the baclofen. Some healthcare providers may prescribe oral medication as a precaution to treat baclofen underdosage in the event ITB withdrawal is occurring. Baclofen withdrawal is considered a potentially lifethreatening medical emergency and therapy will need to be restored as soon as possible. Signs and symptoms of baclofen underdosage or withdrawal can include:

- Sudden increase in muscle tone
- High temperature
- Sweating
- · Itching without hives
- Increased heart rate
- Increased blood pressure
- Rapid breathing
- Confusion or irritability
- Change in mental status
- Insomnia

Top Takeaways for School Considerations

Intrathecal baclofen therapy (ITB) uses an implanted medical device to treat development movement disorders that can cause stiffness, contractures, spasms and pain.

Intrathecal baclofen underdosage, or withdrawal, is a potentially life-threatening medical emergency. School staff should be educated on the student's emergency plan.

Any implanted medical device may require activity precautions or position restrictions. Refer to the manufacturer or specific device manual for safety considerations (e.g., Medtronic).

Becoming familiar with the student's diagnosis, including other movement and mobility needs, will help support their safety and success in their school environment.

Kennedy Krieger Institute

Kennedy Krieger Institute's Specialized Health Needs Interagency Collaboration

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between Kennedy Krieger Institute and the Maryland State Department of Education.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of impaired physical mobility, risk for injury and risk for falls
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Last medication refill date and/or predicted refill schedule
- Student-specific signs and symptoms of underdosage and overdosage
- Assessment of implanted medical device (consider location, date of surgical placement, and device specific information)

- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Equipment troubleshooting (consider equipment/device user manual, alarms)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

Discussion Starters for Educational Team

- 1. Has the school staff been trained to implement the student-specific emergency plan?
- 2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
- 3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?

- 4. Does the student need support with gross or fine motor skills in the classroom?
- 5. Does the student require activity precautions to prevent injury?
- 6. Does the classroom environment support the student's needs and/or equipment (e.g., desk/seating options, maneuverability space, flash pass for bathroom or nurse)?

Resources

Kennedy Krieger Institute: Neurology and Neurogenetics Clinics kennedykrieger.org

Kennedy Krieger Institute: A guide to baclofen therapy kennedykrieger.org/sites/default/files/library/13242_2018BaclofenPumpTherapyParentBooklet_IA1.pdf

Medtronic– IB Therapy medtronic.com/us



Scan QR code or visit <u>KennedyKrieger.org/HealthInformation</u> for more information.

