

Connecting With: DeeDee and her Family



THE FOLLOWING STORY REFLECTS THE EXPERIENCE OF ONE INDIVIDUAL WHO IS RECEIVING MEDTRONIC ITB THERAPYSM (INTRATHECAL BACLOFEN THERAPY) FOR THE TREATMENT OF SEVERE SPASTICITY. MEDTRONIC, INC. INVITED THIS PERSON TO SHARE THIS STORY CANDIDLY. AS YOU READ IT, PLEASE BEAR IN MIND THAT THE EXPERIENCES ARE SPECIFIC TO THIS PARTICULAR INDIVIDUAL. RESULTS VARY; NOT EVERY RESPONSE IS THE SAME.

The house where DeeDee and Blaine live is more than their home, it also is where they run a facility for children with very serious medical conditions. They operate under the same regulations as hospitals and nursing homes in California. DeeDee is studying to become a registered nurse and Blaine is a licensed practical nurse.

In DeeDee and Blaine's care are their two children, Kenny and Michelle, both of whom have severe spasticity. Also living with them in facility care are two children, Trevor and Justin. (The children's names have been changed in this story to protect their privacy.)

DeeDee and Blaine began taking care of Trevor when he was three years old after he was taken from his home due to a non-accidental brain injury. One of the aftereffects of his brain injury is severe spasticity.

"Justin is 13 years old and in protective custody," explains DeeDee. "He came to us last—in November 2004—and has severe cerebral palsy, which has resulted in severe spasticity," DeeDee explains.

Four Children with Severe Spasticity

Caring for four children with severe spasticity is a 'round-the-clock job.

For 21-year-old Michelle, spasticity manifested in tight thigh muscles that kept her legs so tightly closed that diaper changing was almost impossible. Oral medications made her extremely lethargic and affected her breathing.

"Kenny endured severe pain and constant spasms that could only be controlled with drugs that left him heavily sedated. He slept most of the day," DeeDee recalls.

Trevor arrived, suffering from severe spasticity. "We tried the oral baclofen and injection therapies. He was uncomfortable with charley horses in his feet that caused him to screech," says DeeDee.

For Justin, his full body spasms were so intense that even high doses of oral baclofen couldn't provide relief.

Pursuing ITB Therapy

In 1997, Blaine learned about ITB TherapySM (Intrathecal Baclofen Therapy). The couple met with a physician and screening tests were scheduled to determine if Michelle, Kenny, and Trevor were candidates for the therapy. (At this point, Justin was not yet in their care.)

"I held my breath during Michelle's screening test because I so wanted to find something that would give her relief from her tight muscles," DeeDee explains. After she was given the test dosage, it didn't take long before Michelle's knees fell back and her legs separated.

"I hadn't seen her do that in years and I burst into tears," says DeeDee. "It felt like a miracle. That entire afternoon she was so comfortable. I heard her giggle for the first time in six months."

The following week Trevor and Kenny had the screening test and both responded favorably.

“It felt like a miracle. That entire afternoon she was so comfortable.”

Within one month all three children underwent surgery to receive ITB Therapy.

In the weeks following surgery, Michelle experienced an infection at the incision site that was eventually resolved. When the time came for Trevor to have his pump refilled, DeeDee called the hospital to schedule an appointment. A miscommunication resulted in the refill being delayed and the pump ran dry. Unfortunately, Trevor’s physician was on vacation and he was the only healthcare professional at the hospital who knew how to refill the pump. Trevor was given oral medications to control his spasticity until he could see his doctor.

“That experience taught us to never leave a refill appointment without scheduling a return appointment,” DeeDee recalls. “And it taught the hospital to have more than one staff member who could fill the pump.”

Other complications can occur. Surgical complications may include infection, meningitis, paralysis, headache, swelling, bleeding, and bruising. Possible drug-related side effects include loose muscles, drowsiness, nausea/vomiting, headache, and dizziness.

When Justin arrived in DeeDee and Blaine’s care, he, too, took the screening test, was identified as a candidate for ITB Therapy, and eventually had a pump placed.

Four Happy, Smiling Kids

ITB Therapy has had a significant impact on each child’s spasticity.

Michelle now has purposeful arm movement and diaper changing is much easier. She participates in an art class and is learning different painting techniques.

ASK THE Doctor



MICHAEL TURNER, M.D., IS A PEDIATRIC NEUROSURGEON WITH INDIANAPOLIS NEUROSURGICAL GROUP AT METHODIST HOSPITAL.

Q: When is the best time to plan for surgeries?

A: If you are able to choose the time of year a surgery is performed, there are a few things you can take into consideration to minimize inconvenience and promote healing.

Begin by talking to your healthcare team to determine how many hospital, recovery, and rehabilitation days may be needed so you can plan accordingly.

For children, try to coordinate surgery with a school vacation. Scheduling the surgery for the week before a school vacation may allow you to take advantage of the often less-productive days that lead up to the break. The child can then recover over the vacation days. If the child will need to miss a number of school days, ask if the hospital has a tutoring program available.

You also will want to consider the day of the week. My practice tends to perform most SynchroMed® Infusion System surgeries on Mondays or Tuesdays. This way, if there are dosage issues, the physician is available, which may not be the case if the surgery is performed later in the week and the doctor is not available on the weekend.

Summer is a popular time for surgeries, so plan ahead and talk with your doctor about what summertime activities (such as water activities, sports, and other physical activities) could be limited during recovery.

"Kenny has gone from being in a coma-like state to responding to those around him and even understanding their jokes," says DeeDee. "He enjoys outings with Blaine."

Trevor's cognitive abilities are sharper after getting his spasticity under control. He's able to get dressed, play the drums with a music therapist, and use a walker. His speech is improving.

"Justin likes to read and participate in art projects. After he got the pump we realized he was ticklish, and I love that," DeeDee says with a smile.

DeeDee is pleased with ITB Therapy's results. "My advice to anyone who is considering this therapy is to be as persistent as you need to be. Because of the pump I have four happy, smiling kids."

ITB Therapy drug side effects are usually temporary and manageable by adjusting the dose. The most common side effects include loose muscles, drowsiness, nausea/vomiting, headache, and dizziness. Close attention to your doctor's instructions is required since abrupt cessation of intrathecal baclofen can result in high fever, altered mental status, returned spasticity, and muscle rigidity, and in rare cases has been fatal. Once the infusion system is implanted, device complications may include catheter or pump moving within the body or eroding through the skin. The catheter could leak, tear, kink or become disconnected, resulting in underdose or no baclofen infusion. Pump failure may cause overdose or underdose of intrathecal baclofen. For more information, please refer to the last page of this newsletter.

You May Be Wondering ??

HOW CAN I FILL SUMMER MONTHS WITH FUN AND PRODUCTIVE ACTIVITIES?

Summer vacation is an excellent time to explore interests and develop new talents. Attending a recreational camp is one way to engage in new opportunities, meet people, learn responsibilities, and build self-esteem. At camp, everyone is encouraged to test their abilities, to participate, and to progress.

"There is so much to be gained from camping programs," says Matt Rickman, director of Easter Seals' Camp ASCCA in Alabama. "Campers learn to adjust to new environments, develop a sense of self-reliance and leadership, and test their problem-solving skills."

Easter Seals offers camps for adults and children as well as respite programs for caregivers. Matt offers the following suggestions when choosing a camp:

- Find out if the camp is accredited by the American Camp Association, an organization that ensures camps meet requirements for safe and stimulating programs.
- Talk to another parent to learn about their experience with the camp.

- Visit the camp and meet the director and counselors. Bring your child with you. Ask the director about the camp's philosophy and goals to be sure it is a good fit for your family.
- Check on the camp's health and safety procedures. Is there a health professional on staff?
- Ask about counselors' age, training, and experience.
- Determine the ratio of counselors to campers.
- Inquire about the return rate of campers and counselors as a quality indicator.

For more information on summer camps, visit the following web sites:

- Easter Seals: www.easterseals.com
- American Camping Association: www.acacamps.org
- My Summer Camp: www.mysummerncamps.com
- Courage Center: www.courage.org
- National Multiple Sclerosis Society: www.nationalmssociety.org

If your summer plans keep you close to home, you may find you are purchasing toys for outdoor fun. Before you buy, check out www.AblePlay.org, a web site offering independent reviews and information to help when choosing toys for children with special needs.

Connecting With Medtronic ITB TherapySM (Intrathecal Baclofen Therapy)

If you would like more information about Medtronic ITB Therapy, please visit us at www.spasticity.com.

If you would like to subscribe, provide feedback or ideas, share your comments, or submit an address change, you may contact the *Connecting* newsletter via email at spasticity@medtronic.com or call us at 1-800-510-6735, extension 86735.

Clinicians wishing to subscribe to *Connecting* may sign up online at www.MedtronicConnect.com or by sending an email request to itbtherapy@medtroniceducation.com.

If you've wondered if ITB Therapy could work for you, a one-day test may provide the answer. To learn more about the screening test for ITB Therapy, call 1-800-731-2918 for an information packet.

When deciding on the right course of medical treatment, sometimes it is helpful to talk with someone who has had to make a similar decision. Our volunteer ITB Therapy Ambassadors are happy to answer your questions and share their stories. To be connected with an ambassador, call 1-800-503-4110.

If you have a technical question about your pump or therapy, please contact Medtronic Patient Services at 1-800-510-6735.

Finding Out More

For more information, visit the following web sites:

Easter Seals

www.easterseals.com

American Camping Association

www.acacamps.org

National Family Caregivers Association:

www.thefamilycaregiver.org

Maryland Youth Ballet

www.MarylandYouthBallet.org

Able Play

www.AblePlay.org



Ask Joey

Joey,

Last Wednesday our doctor increased my daughter's pump dosage and we've noticed she is more tired during the day. Is this something you have experienced with a change in dosage? Does it take time for your body to adjust?

*Thanks,
Debbie H.*

Hi Debbie,

Good to hear from you!

Currently my dose is 912 mcg a day (2000 mcg concentration). I started at around 200 mcg and slowly increased my dose. Occasionally when I increased it, I felt a little bit sleepy for a day or two afterward. For me, this side effect went away as my body adjusted to the increased medication.

Talk with your daughter's doctor about her specific situation and reaction to the dose increase. Being sleepy isn't fun.

Thanks for writing! Let me know if you have any more questions.

Joey