

# Health Bulletin

## Therapy Helps Youngsters With Severe Spasticity Related To Cerebral Palsy

(NAPSA)—From the time Nick Cugini was diagnosed with a developmental disorder that was later confirmed as cerebral palsy, his parents, Rob and Eve, had actively researched treatment options.

Nick, who has spastic quadriplegia, wanted to be able to walk. But he began to experience a lot of pain and his physical condition regressed. Eve Cugini says, “He was beginning to get into a crouch position, not able to move, and we were up every night with muscle cramps and charley horses.” Up until then, Nick had been mobile with a walker, but Eve and Rob worried that he would soon have to go back to using a wheelchair.

Nick’s physical therapist and his physical medicine and rehabilitation specialist, with whom the Cuginis worked most closely, recommended that they consider ITB™ Therapy (Intrathecal Baclofen Therapy). After a successful screening trial, Nick underwent surgery to receive the pump that delivers the therapy.

“The thought of surgery is very frightening,” Eve admits, “but I had a lot of trust in these people who were an integral part of our lives. We started researching the pump and, of course, immediately found out about Dr. Albright.” She placed a call to Dr. Albright’s office in Pittsburgh. “They were very generous with us, and even hooked us up with a young adult who had had the pump whom Nick and I could talk to about the difference it had made in his life.” Soon afterwards, the family flew to Pittsburgh so that Dr. Albright and his team of specialists at the Children’s Hospital could evaluate Nick. The family felt confident about Dr. Albright’s experience with people with functional ability similar to Nick’s.

The Cuginis made plans to go



**Eleven-year-old Nick Cugini no longer experiences the muscle cramps and spasms that were keeping him up at night.**

ahead with the implant. Eve points out that it is important to schedule surgery in the summer so that the child will have enough time to recover and work on building strength before returning to school. “Nick had the ITB pump implanted in June, spent five days in the hospital, another couple of weeks doing very little, and then began physical therapy with his private therapist.”

The difference in Nick’s physical condition was apparent as soon as he awoke from surgery. “In the hospital he was able to lift his arms over his head for the first time in his life,” Eve recalls. Now, three years later, Eve reports the results are still positive. “There’s been a significant change in the level of function and the pain associated with Nick’s spasticity. We are never up in the middle of the night with any sort of muscle cramps. He walks with his walker at school, and wherever we go, he’s ambulatory.”

To maintain the therapy, Nick’s physical medicine and rehabilitation specialist in Houston refills the pump every three months, and once a year the family travels to Pittsburgh to meet with Dr. Albright for a checkup. Since the pump’s battery life is approximately 4 to 6 years, Nick will undergo another

surgery to replace the pump when he is about 15. “We are already planning to go forward with that surgery. We have weighed the different aspects and have decided we want to continue using the pump. Nick was really the one who made the decision—from the start, he has always been part of the decision-making process,” said Eve.

Eve herself runs a nonprofit organization, the Family to Family Network, which she started because “there’s so much information out there and getting information from another family is such a good way to find out about it.” The organization serves as a support network for parents in the Houston area who have children with disabilities, and also trains parents to be more effective advocates for their children at school, in the medical community and in the community at large.

Reflecting on the family’s experience with ITB Therapy, Eve says: “I really want people to know that I understand how frightening the prospect of surgery can be. I also know the difference it has made in my child’s life. He’s out there, he’s playing baseball and karate, he’s about to earn his sixth belt in karate, he’s doing so many things that he may not have been able to do had he not had this opportunity.”

*The preceding has been a case history of Nick Cugini (now age 11) and the treatment he receives to reduce the severe spasticity associated with cerebral palsy. Results vary; not every individual will receive the same benefits. Side effects can occur.*

*For more information on Family to Family Network, call 713-466-6304 or go to [www.familytofamilynetwork.org](http://www.familytofamilynetwork.org). To learn more about Medtronic ITB Therapy or to locate a center that provides treatment for spasticity, visit [www.managespasticity.com](http://www.managespasticity.com).*