



# Ontario Association for Families of Children with Communication Disorders OAFCCD

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## Opening the Door into Speech

*A Parent's Story by: Judy Chlebak*

On a beautiful May morning in 1997, we brought our two year old son to Sick Children's Hospital in Toronto. Brendan had no idea, of course, what the next two hours would entail, and fell blissfully upon the exciting new toys in the playroom.

When a male nurse offered a friendly hand, he willingly took it, (I believe he thought he was going to another playroom down the hall). Hand in hand, they walked away from us toward the operating room. Brendan never looked back. That was just as well, as I had lost the battle with my tears.

Brendan was born with an enlarged tongue (macroglossia), a symptom of Beckwith-Wiedemann Syndrome. Other symptoms of this rare disorder include abdominal wall defects, accelerated growth, tumours in the kidney, liver, and adrenal glands, and hemihypertrophy (enlargement of one part of the body). Children with Beckwith-Wiedemann (BWS), we learned after Brendan was born, need to be monitored by frequent ultrasounds and blood work. They also need special equipment (Cleft Lip and Palate bottles, nipples and soothers, large size cribs, strollers, and car seats) as well as large size diapers and clothes. Brendan's medical needs would prove to be overwhelming; I would spend hours on the phone tracking down equipment. Brendan would eventually see eight different doctors.

The first two years of Brendan's life were particularly exhausting. Until he could safely use a regular bottle (at 12 months), it took us eight hours a day to feed him, using a Cleft Lip and Palate bottle. He had to be burped every nine swallows. If he caught a cold, he needed hospitalization and suctioning. Despite our careful efforts to isolate him, Brendan did contract several colds and on a number of occasions requiring visits to emergency. His battles with croup were terrifying.

Except for speech and chewing, Brendan met most of his developmental milestones. At the age of two his vocabulary was limited to 30 words, and he couldn't chew solid foods. After the age of two Brendan refused to eat anything but infant cereal and milk. We began to worry about nutrition. As his tongue stuck out he couldn't close his mouth, he drooled copiously. Twice he came close to contracting frostbite.

Brendan became increasingly frustrated by his inability to communicate. Meanwhile, I felt like the mother of the deaf child in the movie Mr. Holland's Opus, who screams, "I don't know what he wants, I don't understand what he is saying!" We began to search for a plastic surgeon that could help Brendan, because the muscles of the tongue are not fully developed until age three, tongue reduction surgery is usually not offered to younger children. We were fortunate to find Dr. John Phillips, who agreed to operate when Brendan was 30 months old. (I will always regret that we were refused surgery earlier, as we might have avoided several of the bad habits that Brendan has found difficult to drop - drinking

instead of eating, refusing new foods, and screaming his demands.) These days I often speak to other parents whose child is facing tongue reduction surgery, and recently spoke to the mother of an 18 month old. How deeply I wish we could have had that opportunity. During the two hour surgery, a pie shaped wedge was cut from the front of Brendan's tongue. Tissue was removed from under the front of the tongue, the sides and the back. In the recovery room, the nurse told us what we could expect to see. Other BWS parents had warned me to expect swelling, blood, black stitches down his tongue, and one stitch taped to his cheek ( to allow the nurses to pull his tongue free if swelling blocked the airway). Brendan was asleep but looked uncomfortable.

The next morning Brendan was wheeled into our room and when we saw him he smiled as widely as he could with his hugely swollen tongue. He then had the worst temper tantrum of his life (my mother had warned me this might happen because Brendan was trying to tell me that he didn't like any of this).

Brendan was supposed to be on morphine for the first 48 hours, but after 30 hours his heart rate slowed from 24 beats to 16, so he was given a "cocktail" of codeine and Tylenol. It was necessary to rinse his mouth with water several times a day, a process he utterly hated: it took two male nurses to hold Brendan down. He was constipated from the pain killers, and needed suppositories. On the fourth day Brendan finally drank from a cup - more or less (for every cup he drank, we soaked a towel held under his chin).

Finally at home, Brendan's nightmares began. Since he couldn't suck, which might have strained his stitches, he also had to go through bottle withdrawal, not an easy time. At first he said little. It obviously hurt him to speak, and the newly shaped tongue felt strange in his mouth. It took a full two months for the stitches to dissolve, and another four months for the swelling to subside.

Brendan began to see a speech therapist once a week. There were many sounds that he couldn't make. When he wanted a drink, he couldn't say milk or cup, so he hung onto the door handle of the refrigerator, and screamed. He could sing two songs, if we sang them very slowly. After the speech therapy, this began to change. The surgery had opened a door, and Brendan entered the world of speech.

My husband and I signed up for "The Hanen Program," a special course for the parents of speech and language delayed children (ages 3 to 6). The parents learn different techniques to encourage speech. The course cost us \$175, and required a doctor's referral.

Parents participating in the Hanen Program attend eight classroom sessions. The Hanen Speech Pathologist visits each home, and videotapes the parents practicing new techniques with their child. Now nearly three years old, Brendan's speech sounded like this: 'Anta' for Santa, "geen" for green, "beu" for blue, and "gook" for bird. It was heartening to replay the same videos a year later, and watch as Brendan learned to label objects correctly "Sheep," then describe them "Blue sheep" or "more sheep," and then begin to experiment with two-word sentences; then five word sentences. His pronunciation became clearer and clearer, During the three months that we attended the Hanen Program, Brendan's vocabulary increased by 70 new words; a phenomenal rate of growth! Today he hardly stops talking.

The Hanen Program promotes lessons that can be practiced during daily routines. I found it easy to do them at home. Whenever I was driving, Brendan demanded that I look at the red car, the blue car, etc, until I became a traffic hazard, never allowed to keep my eyes on the road. (At this point we purchased the Hanen music tape, which kept Brendan busy singing, and I was able to actually watch the road while driving).

I made up a card file with pictures as Brendan mastered each new word. My daughter Erin was a wonderful assistant and to this day will analyze her peer's speech patterns.

Some of the methods that I used with Brendan I had copied from my mother, who taught my brother to read and write. Born with a perceptual problem in an era that failed to recognize or treat it, she single-handedly rescued him from illiteracy. Like my mother, I made games out of learning exercises. When I had to make supper I'd ask my daughter to take over, as my mother did with me as a child.

Our speech therapist, Fern Gitter offered us a new course for parents called the Later Language Parent workshop which runs for four evenings. Parents are given ways to introduce grammar to their child's sentences. You analyze the missing words from your child's speech and learn several ways to model the missing word and exaggerate it through games or daily living activities.

As I am writing this article, Brendan stands beside me, chanting his latest new words. "Dog poo, dog poo, don't sit dog poo." This isn't quite what I had in mind when we opted for surgery and speech therapy, of course, but I have to admit: he's pronouncing every word clearly, and he clearly knows what he's saying. Welcome to the world of speech, my little son.

**Source:** Submitted by Julie Wright, parent, OAFCCD Newsletter September 2004