

H- Parent Stories

Opening the Door into Speech

By Judy Chlebak-Wright

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.

Brendan was born with an enlarged tongue (macroglossia), a symptom of Beckwith-Wiedemann Syndrome. Children with Beckwith-Wiedemann (BWS) need special equipment (Cleft Lip and Palate bottles, nipples and soothers, large size cribs, strollers, and car seats) as well as large-sized diapers and clothes.

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. 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.

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 who could help Brendan. We were fortunate to find Dr. John Phillips, who agreed to operate when Brendan was 30 months old.

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. 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. And then he had the worst temper tantrum of his life (my mother had warned me this might happen – Brendan was trying to tell me that he didn't like any of this).

Because 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*, an eight-week course where parents learn different techniques to encourage speech. The Hanen speech pathologist visits each home, and videotapes the parents practising 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, "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.

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. 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 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 sat 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.