

[Following is a letter Dr. Palmer received from a mother describing the life changing experience her son had because he had a frenectomy. This is a true, but a very frightening story, because it illustrates what little healthcare providers know about frenulums/frenums.]

Dear Dr. Palmer,

I wanted to thank you and tell you my son's story. My son was born in Feb. 2001, and by 22 months was only saying one word: go.

It was clear to my husband and I that he was very intelligent, but we worried. His doctor recommended that we have him evaluated by Early Intervention. When the speech evaluator visited, I brought up the subject of my son's tongue. I had noticed that, when he stuck his tongue out, it never really extended out of his mouth, and I wanted to know if that could be causing the speech problem. She said that it would have no effect. I was a bit confused by that, but deferred to her "expertise."

He was assigned a speech therapist who came twice a week. After three months with no progress, she said to me "Have you thought about getting his tongue checked by an ENT doctor?" I was furious that she had waited three months to mention it, and mad that the evaluator had dismissed my concerns.

At this point, he was 26 months old. I took him to an ENT doctor to be checked. She told me that, yes, he had a tight frenum, but that there was "no established literature" about the effect on speech, and that it would have no effect. She suggested that I might want to get it fixed before his teen years "so that he would be able to kiss properly," and even suggested that I have it done by a dentist in the dentist's office! It was clear to me that she wanted no part of giving me a diagnosis of any kind or providing any treatment to my son.

I immediately started talking to everyone that might know something about it, and searching the internet. My Early Intervention coordinator gave me a phone number of a couple who had been told to wait a year to perform the operation, and regretted it. I also found and downloaded your frenum document (2003).

Between those two inputs, I was given the courage to stand up to the doctor. I went into her office and said "I want this surgery done, and I want you to do it as soon as possible." She did not argue, and scheduled the surgery for the following month. It was performed without a hitch. For six weeks, he didn't utter a single sound. He was constantly moving his tongue and mouth around with a fascinated look on his face - exploring his new possibilities.

Meanwhile, my son was up to his neck in therapy of all kinds. His new speech therapist was telling me that my son was severely autistic and would never function in a normal classroom. The therapist advised me to take him to a

neurologist. Fearing that I would be accused of negligence if I didn't, I took him to the neurologist. The appointment occurred during my son's six weeks of silence following the operation. The neurologist immediately discounted the speech therapist's opinion because "it's clear to me after two minutes with him that he understands every word I'm saying." He was very alarmed at my son's lack of speech. When I explained everything about the tongue and the recent surgery, the neurologist said "That's irrelevant." He wanted to hospitalize my son overnight for heavy testing. I refused, and he was not happy about it.

In the meantime, after the six-week silence, my son started using every word in the book. He's now turning seven, and you can't keep him quiet for five seconds. I have received comments from teachers that his vocabulary and diction are excellent. It took us two more years to completely escape the well-meaning machine of special education, thankfully just before he started kindergarten. He is currently ahead by two years in reading and math skills, has many friends and is a joy to us.

I cry whenever I tell this story, from great relief. If I had not seen your presentation, talked to the right people and stood up to all the various doctors and therapists, I am terrified to think what might have happened to my son, and what might be happening to countless other kids. Please continue to do whatever you can to spread the word about these issues. If you reach even one other parent like me, it's worth it.

Thank you, thank you, thank you. I can never thank you enough.

MR in NY