

Stephanie Mohrbacher

Cleft Palate Foundation's Story of the Month

November 2009

<http://www.cleftline.org/features/som>



Baby Stephanie

One of my earliest memories is of being wheeled down a long hallway in slate-gray pajamas, cheery clowns and balloons dotting my legs and chest. I cried . . . partly out of fear, but mostly in response to my tearful mother, who I could see following us through the cage-like bars raised on the side of my bed. Then she was gone, and a soft-spoken woman was putting something that smelled sickly-sweet over my nose and mouth. I slept.

Mom says I couldn't have been more than a year and a half old at the time and doubts that I could possibly remember such a thing, but there you have it. As a simple myringotomy (ear tube surgery), it certainly wasn't my first operation, nor would it be my last. Here's the funny thing, though: I never remembered them even

touching my mouth. The reconstruction of my hard and soft palate occurred long before any impression could be made upon me, so my memories were always centered around my ears and the world of sound.



A view of Stephanie's cleft

When I was still very little, my favorite singer was Randy Travis. I'd dance around the house, singing my little heart out to "Diggin' Up Bones" and having a grand old time. "Niggi uh mow, I niggi uh mow!" My older sister would laugh and poke good-natured fun. My parents worried. I was subsequently enrolled in a preschool for the handicapped and speech therapy because my mother couldn't stomach the idea of the kids making fun of me once I started kindergarten. It wasn't until I was almost five that I could talk to people and actually be understood. Some would say I haven't shut up since, but I figure that I'm just making up for lost time.



Stephanie's preschool years

Kids will be kids, and a parent can never ensure that their child won't be ridiculed for *something*. Scar-tissue from my reconstructive surgery had caused severe crowding in my teeth, and the children's movie *The Land Before Time* was just becoming popular. This combination resulted in the lovely nickname "Shark Tooth" for most of my elementary years. Eventually, the State took pity on my family and fully

Stephanie Mohrbacher

Cleft Palate Foundation's Story of the Month

November 2009

<http://www.cleftline.org/features/som>

paid for my orthodontic work. Four years of braces and one palate expander later, most people would not even guess that I was born with a cleft palate. The only outward clues would be my slightly recessive profile and almost nonexistent upper lip.

My hearing was another story entirely. My ENT tells me that ear issues are far from uncommon in cleft palate patients; I was no exception. Many a night I would wake up in tears from the pain in my head. Ear aches became such a

regular occurrence in our household that my stepmother would already have home remedies in hand before answering my knock in the middle of the night. Many more myringotomies followed, but my hearing continued to deteriorate. Eventually, it was discovered that I had developed a condition called Cholesteatoma. This meant that cysts would form in my ears and wreak havoc upon everything they contacted. Multiple surgeries later, I wound up with severe hearing loss in my right ear and mild in my left.

Life goes on, and children grow up. The surgeries tapered off as I finally finished high school. It was time to decide what to do with my life and the experiences it had brought me. Floating along aimlessly through junior college general education, I finally realized that my past and personality

had placed me in a uniquely appropriate place; I could help and understand people going through what I had. As of now, I am happily enrolled in an audiology program and am well on my way to earning my Doctorate of Audiology (AuD).

Along this road of self-discovery, I met a wonderful man who asked me to be his wife. We married in October of 2008. He doesn't mind the many ENT visits, dizzy spells, and constant repetition because I simply did not hear him the first time. Neither does he pay any heed to the chance that

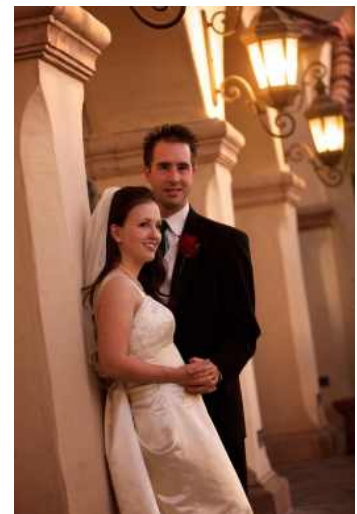
our children could very well have the same problems. Do I worry? Of course I do. I know the numbers in regards to cleft palate patients passing the condition on to their children. Naturally, I would not *choose* to pass this on. Surgeries are never fun, and no parent would wish that upon their child. However, knowing what I do, I know that it does not have to be a negative thing. Yes, I was born with a "hole in my throat." Regardless, I am healthy and whole, and I feel as though this condition helped me find my place in the world. Hopefully, should our future children travel a similar path, it will do the same for them.



Elementary school



High school graduation



October 2008



"I am healthy and whole..."