

July 2007

My name is Jeremy Dale and I am 7 years old. I was born with a craniofacial abnormality called Goldenhar syndrome which affects all children a little differently. For me, Goldenhar meant a large left facial cleft, extreme cleft palate, the absence of a left ear, an underdeveloped left eye and 2 hemi-vertebrae located in the middle of my spine and at the top of my spine causing congenital scoliosis. I also arrived 7 weeks early, was 3 lbs 10 oz, and spent the first six weeks of my life in the Neonatal Intensive Care Unit.

So far I have had 20 surgeries to begin reconstructing my face. From the time I was born I've eaten through a feeding tube which gets connected to a button in my belly. My first facial surgery was to close up the hole in my face. I was 5 months old and barely 10 pounds. When I was 2 years old, the doctors did a spinal fusion to remove the hemi-vertebrae in my spine and I was in a body cast for 4½ months! Most of the facial surgeries that I've had have included adding bone to my face. The doctors have taken lots of bone from my ribs, hips and some from my head. I've had reconstruction in my cheek, around my eye and in my jaw. I have a hand-painted prosthetic in my left eye that matches my right eye exactly! When I'm about 8 or 9 I'll be ready for the doctors to make me a left ear. My most recent procedure was jaw distraction where the doctors actually stretched my jaw bones. This wasn't very fun, but at the end my jaw was big enough to open my airway and the doctors were able to remove the tracheostomy I had for 6 years! I'm finally able to go to school without a nurse and I feel very free!

I might look a little different, but I'm a typical kid. I just finished 1st grade and I have a lot of friends. My primary method of communication is through sign. I like to talk all of the time, but it's very hard to understand me. I love to ski and I've played both soccer and tee ball. I love to play with race cars, watch movies and read books.

I became involved with Children's Craniofacial Association 4 years ago when we attended our first annual family retreat in Washington D.C. It was such an amazing experience for both me and my parents. I met so many other kids just like me. Since then my parents have been extremely active with CCA. We look forward to the retreats every year. In addition to Washington, D.C., my family and I have been to retreats in Tempe, AZ, Nashville, TN, Hershey, PA and Salt Lake City, UT. Some of my best friends are kids that I've met at the retreats.



Jeremy at 2 months - before any facial reconstruction



Jeremy at 7 years old