

Jake's Story, as told by his mom Kristi:

Jake Stephan was born at 39 weeks via c-section on June 11, 2009 at Morristown Memorial Hospital. I remember hearing the nurses asking if he was a breeched baby. I recall looking at Jake and something seemed 'off' about his head shape. The next morning, our pediatrician came in and said, "everything seems OK, but Jake's sagittal suture seems to be closed". What????!! How can that be? And that's how my Craniosynostosis Journey began.



When Jake was 12 days old, we went to visit Dr. Jeffery Wisoff at the NYU Craniofacial Center in New York City. A team of specialists all diagnosed Jake. I remember just sitting there crying holding my new beautiful baby. Surgery was scheduled for September 8th. I went home and started my research. The Internet had so much information, but it really made me more scared about my Cranio Journey. I stopped looking and just loved my baby the best I could. My husband, 3 1/2 year old twins Danny and Britt, and Jake and I all went on our family vacation. I decided to take along Dr. Wisoff's literature and info packet that his office gave to us. Looking through it, I noticed that the Jorge Posada Foundation was a source for families like ours. I immediately emailed the foundation and heard from Laura Posada within hours. She put me in touch with her team and within a day I found my mentor, Cathy. I remember calling Cathy from vacation and just talking out everything from our rented beach house. She really put my mind at ease and gave me the confidence I needed to continue on our Cranio Journey.



The morning of the surgery I laid in bed holding Jake, rubbing his head, knowing this would be the last time I would ever see him without a scar. It was so scary. NYU took him right in and that wait time felt like an eternity. It took them an hour and a half to get the IVs in where they had to open his wrists and he has scars there now. The nurse brought out a cup of his hair for his first haircut. Finally, the surgery was over and was a success! We had to wait about an hour to see Jake.



There Little Man Jake was....in his miniature hospital bed, in a little yellow gown, with IVs and a huge head bandage. I just cared that he was all right. The next 24 hours were brutal. Jake would wake up and cry and I tried the best I could to comfort him. My husband had to go back home to take care of the twins, so it was just the two of us. Jake was released from the hospital the next day. They gave him a little morphine and told me to stick to Tylenol for the next week or so. I was so nervous. I carried Jake around all day in a baby Bjorn to keep him upright for the swelling, but really so that I wouldn't drop him. He slept next to me in a boppy at night. The next day, the swelling went down and one of his eyes opened. The following day, Jake looked about 90% back to normal. I think taking the bandage off and caring for the wound was extremely hard. It just looked like it hurt, but Jake's head started to look "normal" after a few days, not like the football shape it once was.



Today, Jake is a normally functioning baby. As I write this, he is 10 1/2 months old. I think the Cranio Journey has given me a love that I have never known. We keep his head covered from the sun, but indoors we show his scar with pride. Jake still has a "thumbprint" of a soft spot on his head, which Dr. Wisoff said that it might need a Cranial Plug, but they don't do that until 3 or 4 years of age.



Little Man Jake. The happiest baby most people have ever met. I'm so glad he's in my life.