

David's Journey

David was diagnosed with Sagittal Craniosynostosis at his two month checkup. Our Pediatrician sent us to get x-rays right away. Our first neurosurgeon we saw told us it was just a cosmetic issue, and to go home and watch his heads growth. As a mother I didn't feel right about the information we received so I started researching. I wanted to find out everything I could about Craniosynostosis. In my findings I came across the Jorge Posada Foundation and a lady from the UK who's son has Craniosynostosis. What I knew in my heart to be true was becoming real; this WAS NOT just a cosmetic issue. It was a very real and serious condition. I asked our pediatrician to refer us to a second opinion. We went to The University of Virginia and saw Dr. Jane Jr. He confirmed that David had Sagittal Craniosynostosis and needed surgery. We were sent to see another member of his team Dr. Lin a plastic surgeon; together they decided that David's condition was to advanced for the minor of the two surgery's out there. We decided to wait until David was six months old and go with the more extensive surgery that would hopefully correct his condition without another surgery's and the use of a helmet. At six months of age we packed up our youngest son and drove two hours to UVA for surgery. Dr. Jane and his team were wonderful at preparing us for what to expect. We had a nurse who called us with updates every two hours. It was the longest six hours in my life thus far. After surgery David was a little trooper, he dealt with swelling and pain like nothing had happened. A few times I could tell my little guy wasn't doing well, but the nurses were great at helping and stopping the pain. Everyone at UVA was helpful in every way. The staff at the hospital and all of the doctors' offices made a troubling experience seem not as serious and stressful as it was underneath. I think that if one person would have been different on this journey, I might not have gotten through it as easily as it seems I did. I was grateful for all the thoughts and prayers that strangers said for my son and our family. Today I try to treat him like nothing had happened. I don't hide his scar with long hair and I plan on telling him that his scar is something to be proud of. I took pictures everyday while we were in the hospital, and I am making him a proud of my scar book to keep alongside his baby book. We have had a couple of setbacks, like not learning to walk until he was 16 months old with the help of a physical therapist. But nothing major. Every doctor's visit ends with the words "he looks great". We couldn't be happier with David and all the wonderful people we have meet on this journey of having a Cranio Kid.