

## Meet “Cranio Kid” T.J. Greenfield

On September 2, 1999 we (Tom and Lisa Jo Greenfield of Skaneateles, New York) welcomed our second son, T.J. (Thomas James) Greenfield into the world. He was a happy, healthy baby boy. Although his head seemed to be a bit misshapen immediately after birth, the doctors assured us that it was a result of the birthing process and in a few weeks it would appear normal.

After a few weeks, however, we were still concerned with the shape of T.J.’s head. At his two month well visit, T.J.’s pediatrician also became concerned and started questioning how he slept. When he found out that T.J. slept on his stomach and not his back, he immediately ordered x-rays.

T.J. AT TWO MONTHS OLD



We went directly from the pediatric office to Diagnostic Imaging to have a full set of head x-rays taken. Within two hours, the x-rays were reviewed and preliminary results showed that T.J. had Sagittal Craniosynostosis. A formal diagnosis by a pediatric neurosurgeon in Syracuse, New York was necessary before we could review what surgical options were available to us.

Upon review of T.J.’s x-rays, the pediatric neurosurgeon immediately confirmed the diagnosis. He then proceeded to tell us exactly what he was going to do to correct T.J.’s condition.

T.J.’s pediatrician had diagnosed only one other case of craniosynostosis in ten years, and ironically enough, it was six months prior to ours. In an effort to be of assistance, he connected us with this family whose son Kyle was a “cranio kid”. Kyle’s parents soon became our mentors.

Kyle’s father was in pharmaceutical sales and connected throughout the United States. He researched all of the doctors and hospitals with craniofacial teams in the United States. Through his research he discovered two neurosurgeons that

were performing an endoscopic strip craniectomy. This procedure was considered to be experimental at that time.

The doctors who pioneered the endoscopic procedure, Dr. David Jimenez and Dr. Constance Barone, are a husband and wife team. When their first son was born, they thought that if he had craniosynostosis, as parents, they too would struggle with having to put him through the traditional surgery. Thus, this breakthrough procedure, the endoscopic strip craniectomy, was created.

Kyle's parents opted for this "experimental surgery." They were very passionate about their most successful experience and shared every detail with us about the endoscopic procedure. We learned that the first year of a baby's life is when the skull grows the fastest. If surgery is done early, within five to six months, the baby's own bone would grow back in naturally. Kyle's surgery was done within six months and thanks to Kyle's parents, we were able to see first hand his perfectly shaped head. We also saw the helmet that Kyle had to wear to help shape his skull post surgery.

While we were initially overwhelmed with the information Kyle's family shared with us, it wasn't long before we knew in our hearts that we had to try the experimental surgery. It just felt right. So, the day after we met Kyle, we contacted Dr. Jimenez's nurse, Cathy Cartwright and sent T.J.'s x-rays express mail to the Children's Hospital at the University of Columbia in Columbia, Missouri. At that time, Drs. Jimenez and Barone were practicing at this location. (Currently, they are practicing at the UT Health Science Center at San Antonio, Texas). Within two weeks of our initial contact, T.J.'s x-rays were reviewed, a surgery date was scheduled and we were off to Columbia.

Upon our arrival, we checked in to the Ronald McDonald house and then met with Cathy. She informed us that we were not going to meet the doctors right away because they had been sick and that T.J.'s surgery would be delayed two days as a result.

On December 1, 1999 we were introduced to Dr. Jimenez and Dr. Barone. Literally, our meeting with the doctors was scheduled about two hours before surgery. Although it was a bit frightening, both doctors were extremely professional and answered all of our questions. It was apparent that they really did understand how we felt and genuinely cared about helping us and our baby.

Drs. Jimenez and Barone explained the exact procedure they were going to perform on T.J. By using an endoscope they would make two small incisions, one on top and the other on the back of his head. These incisions would allow them to endoscopically separate the tissue from the bone. Once the separation was complete, the sagittal sutures would be opened by removing a one by four inch piece of bone from the top of T.J.'s head. When the procedure was finished the incisions would then be closed using surgical glue.

Being completely comfortable with the doctors and T.J.'s pending surgery, we met the anesthesiologist, who appeared to be equally skilled in his profession. It was one of the hardest things I have ever had to do, but the next step was to hand T.J. over to the nurse who proceeded to take him to prep for the surgery. I still choke up thinking about it!!

Our overall experience with the surgery was an eleven on a scale from one to ten. We were notified the minute T.J.'s surgery started and ended and allowed to hold him immediately post op. Everyone we came in contact with was confident, re-assuring and professional. If this were not the case, I would never have given them my son, especially after only meeting them just before the surgery was scheduled to be done.

T.J. POST OP



T.J. did not have any complications and was released from the hospital twenty-four hours after surgery on minimal over the counter medications. We gave him Tylenol and Motrin (alternating between the two) every four hours. It was amazing to us how quickly he recovered. He was sleeping and eating as normal and there was no infection, transfusions or fever. T.J. was a bit cranky for a few days, but each day the swelling in his head decreased and within two weeks he had a helmet and we were on our way home.

T.J. 4 DAYS AFTER SURGERY



The helmet was made out of plexi-glass from a mold of T.J.'s skull. A stocking was placed over his head, slits for his eyes and nose were cut out and then very quickly, a plaster cast was made. The finished helmet had holes in the top to let the "heat" out. A baby cools down by letting heat out through their head and feet. T.J. never wore socks, even in the middle of winter, for this reason. He was always warm and in fact, we would often see condensation in the helmet from this release.

## THE MAKING OF T.J.'S FIRST HELMET



As T.J.'s head grew and his helmet became too small we travelled back to Columbia to have a new one made. T. J. wore a helmet until he was a year old, so three trips back to see the prosthetic specialist were necessary. Each time, the protocol was the same.

T.J. 2 ½ MONTHS POST SURGERY



Throughout T.J.'s journey we kept a journal. Whenever we had a question or a concern we would refer back to the journal and then pick up the phone and call. The doctors, along with their team, were always available to help us.

T.J. 4 MONTHS OLD IN FLORIDA ON THE BEACH



T.J. LEARNS TO WALK



T.J. was the 58th child to have the endoscopic strip craniectomy performed. Even being so early in the experimental phase, we have NO regrets about our decision to pursue this type of procedure for T.J. To this day, his head is perfect! His own bone grew back in beautifully and there are no screws or plates in his head. He looks and acts like a normal child. If faced with the same situation today, ten years later, we would make the same decision.

DR. JIMENEZ AND T.J. (AGE 1)



For many years we have been on a personal mission to create an awareness of craniosynostosis. As parents, we believe in Drs. Jimenez and Barone and the endoscopic procedure they developed. It is no longer considered “experimental” and its success has been documented in various medical journals. While it may not be an option for all children, it is certainly a viable option for most infants who are diagnosed with craniosynostosis.

As a family, we would like to offer kudos to The Jorge Posada Foundation. When we started our journey, such resources were not available. The Posada’s campaign to create awareness, provide information, education, guidance and monetary assistance to those affected by craniosynostosis is invaluable!

T.J. AGE 10







Dedicated to T.J. by his Mom (Lisa Jo), Dad (Tom) and Brother (Patrick)  
June 3, 2010

