

Cranio Kids

By Lisa Jo Greenfield

This past fall while doing some research on glutathione, I was interrupted by my husband yelling, "Lisa, come quick, you have to see this!" I ran into the living room just in time to view a segment on the Major League Baseball channel about The Jorge Posada Foundation and Craniosynostosis.

I was glued to the TV. As information on the foundation was presented, I began to well up with tears. Ten years ago, at the age of two months, my son TJ was diagnosed with Craniosynostosis.

Craniosynostosis is defined by the Merriam-Webster Dictionary as "pre-mature fusion of the sutures of the skull." Basically, a baby's skull is made up of five pliable bones and held together by fibrous tissue called sutures. When the sutures (soft spot) close prematurely, the skull can't expand and the brain can't grow equally in all directions. This causes the skull to be misshapen and in some cases, there is significant pressure on the brain.

It is estimated that 1 in 2,100 infants are born with Craniosynostosis. There is no known cause for this condition and surgery is required to correct it. Through the research I have done, I was able to find a link between cigarette smoking, low glutathione and craniosynostosis. However, it is not conclusive.

Early diagnosis and treatment are critical. If left untreated, Craniosynostosis can cause developmental disabilities, blindness and hearing loss. Unfortunately, misdiagnosis is common, especially in light of the SIDS campaign advocating that babies sleep on their backs. Babies who sleep on their backs often develop flat spots and have misshapen heads, which can be confused with Craniosynostosis.

In TJ's case, we were fortunate to have a pediatrician who was fully versed on Craniosynostosis. At our two month well visit he immediately ordered an x-ray and we were able to quickly confirm the diagnosis. He then provided us with information on the two types of surgeries that were available.

After extensive research, my husband and I decided to have an Endoscopic Strip Craniectomy performed on TJ. This surgery was considered to be experimental at the time, but was much less invasive and not nearly as traumatic as the traditional surgery.

TJ was the 58th infant to have this "experimental" procedure done in the United States and it was overwhelmingly successful. There were no long hospital stays, blood transfusions or infections, which are common with the traditional surgery. To date, TJ's head is perfectly shaped and no additional surgeries have been necessary.

Since TJ's surgery, the Endoscopic Strip Craniectomy has been fully acknowledged and accepted by the medical community. Favorable results have been published in peer reviewed medical journals as well as in many other publications. For more information on the Endoscopic Strip Craniectomy and doctors David Jimenez and Constance Barone, the pioneers of this procedure, go to universityhealthsystem.com/.

As the mother of a "Cranio Kid," I have worked to create awareness of this condition. So, as you can imagine, hearing about The Jorge Posada Foundation was significant to me.

The purpose of The Jorge Posada Foundation is to provide emotional and financial support to families and kids who are diagnosed with Craniosynostosis and to create awareness about the condition. As a member of the Mentors Network, I would like to invite you visit The Jorge Posada Foundation on line at jorgeposadafoundation.org.

Lisa Jo Greenfield is a Skaneateles resident and proprietor of Essential Health Solutions. Her column will appear the second week of each month. She is committed to educating local residents and creating awareness surrounding topics relative to personal health and Essential Health Solutions. For more information about Essential Health Solutions, log onto LookLiveFeelBetter.com.

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