

Isabel's Odyssey...."Keep the faith" as told my her mother, Carol Braun

As brand new parents of an eight week old baby girl, my husband, Michael, and I set out for a routine well visit to our pediatrician's office with our precious gift, Isabel Patrice born 8/25/1997. Although we suspected that this little darling's head was not quite perfect, we never dreamed that we would later learn our sweet new one would require surgery for craniosynostosis.

"Keep the faith"

My beloved father, Raymond Paul Kalafsky, who is deceased since 1991 (he passed away from cancer at 53 years old) would always utter those three words, "Keep the Faith", to his six children and wonderful wife. These three syllables were the impetus for my drive to move forward. Once I learned on 10/23/1997 that Isabel was affected by a narrowing of the sagittal and coronal sutures and that these findings were consistent with craniosynostosis, I became keenly aware that I had to prepare myself and embark on an unexpected journey.

At times, I was completely incoherent and plagued with indecision as to what to do next. Yet, with the strength that I found in the support of my best friend who is my husband, my 2 sisters, Judi (a teacher and mother of 3) and Ann (a nurse), and my incredible Mom, I forged ahead and remained awake the entire night diligently searching on the internet (which was not like it is today, so rich with information). I procured adequate information to prepare for a meeting that I had secured with the head of Pediatric Neurosurgery at NYU Medical Center, Dr. Jeffrey Wisoff.

Incredibly understanding, gentle, and appropriately esteemed in his profession, Dr. Wisoff approached Michael and me with the utmost respect. He held little Isabel in his arms and embraced her like she was one of his own. On October 24, 1997, my spouse and I learned that Isabel's head circumference was 41 cm. The shape of her skull was elongated from front to back and protruding at the sides. There was a ridge beginning approximately 1 cm posterior to the fontanelle, extending along the sagittal suture in the midline and then extending bilaterally to the sides along the proximal 2 to 3 cm of the lambdoid suture. There was posterior scaphocephaly with a marked occipital protuberance. Skull xrays confirmed posterior sagittal and proximal lambdoid synostosis.

An extended vertex craniectomy and cranial vault remodelling were performed at NYU in Manhattan for correcting her skull on Tuesday, November 4, 1997; Isabel was just 10 weeks. A day that I shall never forget, I vividly recall that was operated on a Tuesday morning and returned home on Friday morning. She did run a high fever at NYU and required a blood transfusion. Isabel's head was bandaged from the surgery and she had very swollen face post op. Her eyes were little slits as the surgery was performed lying prone and therefore, all the fluid rushed to her head. My daughter's face was slightly challenging to look at in the recovery room and for a few days while in the hospital. When Dr. Wisoff explained to me that the surgery was complete, a wave of genuine euphoria surged through me. It was incredible. Such intense emotions were experienced by Michael and me. It was a feeling of such relief yet, I had the anticipatory sense that what I was about to face was not pleasant.

Once in the recovery room, I encountered such a horrendous ordeal; what I thought was an issue with my surroundings was truly a war to be waged with my emotions. An elderly man near Isabel's bed was profusely vomiting. There was my 10 week old infant bandaged, bruised and battered. Looking at the clock at that very moment made me realize how weak I was. I asked God to fast forward my life, because I was not strong enough to cope with this inner turmoil. I was broken....I was damaged...I was a mess. After a few moments, I had an epiphany. Keep the faith! This was not about me...I needed to pull myself together and care for my new baby. I mustered up the strength to check her tubes and lines and sat in the dark, dank room with my husband; we were hoping for her speedy recovery. Isabel did fight off an unusually high fever, needed a blood transfusion, but as stated earlier, she endured the surgery and came home in 2 1/2 days....

My profoundly vivid memory is driving over the George Washington Bridge from NYC to New Jersey. I literally looked behind me and saw the NY skyline. Inside those buildings were kids at NYU who had broken hearts, hearts that were literally not functioning. They probably would not have the opportunities that awaited my daughter in her future. I was saddened to think of all those babies that I left behind. Perhaps, that moment should be a gentle reminder of how fortunate we are. That memory is indelible in my head. I was granted the time to take my baby out of the hospital and she would never have to return there again. Today, she is thriving as a 13 year old...loves life, takes advantage of every opportunity that comes her way and is incredibly passionate and successful.

Once she was home, I breast fed her on a pillow to prop up her head. Eating was no problem for her despite the wrapping on her head. The swelling went down after a few days and the bruising around her eyes diminished by the weekend. Michael and I gratefully took her out of the home within a week; her swelling and bruising had abated.

One week post op, I took her back into NYC for a follow up. She had other visits 10 days post op and 3 weeks after. Isabel returned to the neurosurgeon after 6 months and one year. After that, the physician felt it was no longer necessary to see my daughter. Isabel wore hats for a long time since her head had been shaved and she had a 10 inch zig zag scar running down the center of her skull. (I treated her to an amazing hat at Nordstrom that cost more than I would ever spend on shoes for me) I photographed her in the hat for her 3 month picture. She was still bald, but God would soon grant her an amazing head of hair! Other than her scar, she does have some bumps on her head, but the hair certainly covers her scar beautifully.

Fast forward more than 13 years later, and today, Isabel is an incredible teenager. She is a straight A student who aspires to be a pediatrician; her talents are endless. She is a member of a touring musical troupe in Morristown, NJ, where she performed recently with Kenny Rogers. Isabel starred "Seussical" this past summer in Princeton at the Westminster Choir College and is currently cast as Belle in "Beauty and the Beast" in Randolph, NJ, her hometown. A Girl Scout, a member of the Student Government Association in her Middle School, she is an avid dancer; Isabel takes Lyrical and Jazz lessons, plays in a select orchestra at her school as a violist and sings in the choir and select choir. Her spare time is limited, but she immensely enjoys spending time with her siblings, CJ, 10, and Ethan, 5.

Although she never had a chance to meet Grandpa Ray, Isabel's odyssey was marked by her grandfather's 3 words, "Keep the Faith".