



Newborn Screening
Saves Babies
One Foot
at a Time

Katie

IN LOVING MEMORY OF KATHLEEN CELESTE BOIROS OCTOBER 24, 2002 - JULY 11, 2003. LOST TO AN UNCLASSIFIED FATTY ACID OXYDATION DISORDER (U-FAOD).

Kathleen Celeste Boiros was born on October 24th, 2002. She was born on her Auntie Eileen's birthday and she was named after her great-aunt & mommy's Godmother K.C. (Aunt Casey). Auntie Pam would be her Godmother and Uncle Jeff her Godfather. She'd be called Katie.

From her very beginning, Katie was full of surprises! She inspired love and happiness to all she touched. Katie was born into the world via cesarean section at 34 weeks. She was delivered early due to concerns of cord compression. She weighed only 4 lbs and 13 oz and was 17.5 inches long. She was tiny and 'fuzzy' with little hairs, but otherwise perfect. She took to the breast within her first hours.



Several hours after her birth, she began making breathing noises (called Strider). As a precaution, she was transferred to the nearest NICU hospital in the neighboring state of Rhode Island. 21 days later, after 2 Bronchoscopies, a battery of testing and a potentially critical mistake up with her IV & perc tube, Katie headed home from the hospital with the squeak still in her breath. She's proved in the hospital that she was strong and determined baby. Katie quickly out grew the squeak and her growth chart indicated she was gaining weight at a "textbook" rate.

The hair on her head grew long and thick as did her expressive eyebrows and dark curly eyelashes. A strawberry birthmark began forming on the right side of her lower cheek & chin. It bloomed into the beauty-mark that gave her precious face character but paled in comparison to her big bright and wondrous brown eyes.

Katie was such a happy baby all the time. She loved to take a bath. She was very gentle as she explored the sense of touch with her cat, the grass, the sand and whatever else she tenderly reached for. She enjoyed music, especially the Fishy song that she 'danced' to. She liked lots of different toys, but her favorite thing to play with, second to her feet and piggies (toes), was "guy" - a little fabric gingerbread man. The sight of guy never failed to make her expression light up and she'd often practice conversation with him. She didn't suck her thumb or take to a binky very much, but she found comfort in sleeping with her pink Winnie the Pooh blanket. By 4 months old, Katie was sleeping through the night.

Katie traveled beyond the state of MA where she lived to visit many corners of the U.S. and meet her family. She adapted well to the break in her routine and maintained her good nature during trips to CT, FL, NV, and CA. She was the type of baby that would make you ask not, 'What shall I teach you today?', but, 'What more will I learn from you today?'.

She never cried an inconsolable cry. She was never sick or ill - until the week before she died and, not even then did she cry.

Around July 1st, 2002, Katie, along with many of the other babies in her day care and her Mommy and Daddy, came down with a stomach virus. She vomited 2 or 3 times, then seemed to bounce back to her usual self after a couple of days. By the 4th of July, she was feeling much better and enjoyed the weekend on the boat and visiting family and friends.

On Tuesday, July 8th, 2002, Katie's day care called to say that Katie had vomited after her lunch. Considering that she'd just recovered from the previous stomach virus, she visited the Pediatrician the following day - Wednesday July 9th. She was thought to have still been recovering, and may have been a little "cranky" and groaning because she was teething - so she was sent home with instructions on how to administer Infant Tylenol. She went home, vomited, then later, was able to hold down dinner - until several hours after going to bed.

On Thursday morning, July 10th, she went back to the doctor. She was visibly weaker and her groaning became short shallow breaths to which the doctor attributed to "discomfort". It seemed un concerning to the doctor at the time that she was obviously working hard to breath and that her pattern of vomiting had been so sporadic (rather than pay attention to the frequency of her vomiting, the doctor thought it best to 'average' how many times over the past week had she thrown up). Again, Katie was sent home and put on a liquid diet.

She was visibly weak, but never cried, in fact, she tried to muster up a giggle when her Daddy played silly-head with her. That night, she slept on the couch with Mommy and Daddy alternating shifts so she could keep sipping Pedaled throughout the night. That would be her last night.

First thing Friday morning, July 11th, 2003, Katie went back to the doctor. This time, she saw a different doctor because her primary went on vacation. After several blood tests and a urine sample was taken, she left the doctors and was headed for the hospital for IV and observation. She arrived at the hospital by 10:45am. By noon, she'd had chest x-rays and was laying in a (ridiculously) large bed in a private room in the local hospital pediatric ward. The Pediatrician called in orders while he finished his office visits.

By 4:30, the room was bustling with nurses and techs and various other hospital staff. Some time around 4:45, the doctor had arrived and he was making arrangements to have her transferred to Boston's Children's Hospital - Pneumonia and the level of acid in her blood test results were the primary concerns. They were talking about intubating her. At just after 5:00p.m., to our absolute horror, Katie stopped breathing right there in front of us - just stopped breathing.

The doctor's tried to resuscitate her for over 45 minutes before the doctor who'd seen her for the first time that morning had to break the news that "...she didn't make it". And just like that, her life ended.

Four months later, the autopsy results indicated with '90% accuracy' that Katie had a form of Fatty Acid Oxidation Disorder. Though Katie had been tested for MCADD, the results of the test were negative.

We will strive to raise the awareness of the importance of Infant Screening as well as hold fund-raising events in Katie's honor and donate proceeds to the NICU and to the research of FAOD so that Katie will not have died in vain.

Though Katie is gone from this world, her memory will live on forever in the hearts of those who knew and loved her. She truly was a living angel.

Written July 2004 by Maureen Boiros, Mother of Katie