

On The Cover



Vivienne's Journey

Vivienne Esme Martin was born at 4:24pm on 4/24/08, 6 lbs 14 oz and 19" big. All new parents say this, but of course we were instantaneously in love.

With an extremely difficult labor and delivery, it was a relief to have our healthy, happy, beautiful, sweet lil' baby girl at home with us. When I think back to the first two months of her life, it is pure heaven. Of course, we were tormented by angst while we figured out how to care for such a tiny, needy, stubborn little creature. We slept only a couple of hours a day, alternating between sleeping in bed and Vivi-vigils on the couch. With my difficult recovery, Justin took on the bulk of childcare and let me sleep 8 glorious hours every night. Sleep was such a commodity, that my only birthday present to Justin (other than delivering the Precious) was his own full night of sleep.

As the weeks went on, we celebrated each additional week of life. Things calmed, and we

worked into a schedule and a good family way of life. Vivi began to sleep through the

night on Memorial Day weekend. From day one she has been Daddy's Girl, with eyes only for Daddy in the world. Slowly she gained as deep an appreciation

for Mama, too, and the three of us were in heaven. As I returned to work in early June, we were thrilled to have the family together every day, with Justin caring for Vivi while I worked, and taking care of all of us. We were overjoyed by each milestone, but nothing compared to that first smile. We began to build a Flickr page to share adorable photos with family. In the coming weeks, we also made a little video homage to Vivienne.

At two months, we packed

Princess cry during routine immunizations. We reviewed milestones and went through the exam, with the constant reporting that Vivienne was doing wonderfully. Then things turned a little bit.

The doctor became worried about

Vivienne's head circumference. When Vivi was born, her height and length were in about the 30th percentile, but her head circumference was 58th percentile. At the two-month visit on June 25, her head circumference was off the charts at 95th

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percentile. Out of an abundance of caution, said the doctor, she recommended we go to Children's Hospital of Philadelphia (CHOP) for a head ultrasound. She pointed out that with Vivienne doing so well, it was very unlikely anything was wrong. When the head ultrasound showed massive amounts of fluid in her ventricles, a diagnosis called benign hydrocephalus was suggested. A minor surgery would be done to install a VP Shunt to drain the excess fluid into her abdomen.

We were heartbroken, terrified. As we were transferred into the NICU with Vivienne, we tried hard to find balance between optimism and the feeling that an unfair catas-



Vivienne Esme Martin

Vivienne up for her 2-month well baby visit with the pediatrician. The biggest thing on our mind was how agonized we would be to watch our Little

trophe had struck. All that time saying "at least the baby is healthy and happy" after my c-section and hysterectomy was out the window. As we snuggled to sleep, however, our minds began to adapt and we woke up hopeful for the future. I even bought a U Penn shirt, and proudly said all of this would be nothing more than a great college admissions essay for Vivienne sometime down the road. We were scared, but loving and hopeful.

With surgery scheduled for June 27, an MRI was done on June 26 to obtain additional imaging in preparation for surgery and for diagnostics. Over the next few days, a horrific picture emerged. Vivienne had a massive posterior fossa tumor, or in English, an egg-sized tumor in the area of her brain near the cerebellum. The cerebellum works on muscle control, coordination, balance, and sensory perception.

Over the next weeks, news continued to get worse. Diagnostically, it was felt the tumor was either a Primitive Neuroectodermal Tumor (PNET), which would be bad, or an Atypical Teratoid Rhabdoid Tumor (ATRT), which would be worse. After weeks of hoping for a PNET, given messages of hope from the oncologists in that Vivienne was doing so well, showing no developmental or neurologic impairment, we

went for a second diagnostic

The MRI showed growth in the

surgery to remove the brain tumor, explaining it was far too risky and would likely result in Vivi's death during surgery. While we were on the verge of giving up, a family member suggested that LeBonheur in Memphis had the best neurosurgeon in the world who might be willing to try surgery when others refused. We contacted LeBonheur, and the wonderful folks there and at St. Jude Childrens Research Hospital considered Vivienne's case.

In the meantime, we obtained a genetic test that

showed that Vivienne has a germ line mutation of the INI1 gene, resulting in a definitive diagnosis of ATRT. Neither Justin nor I are carriers of the mutation. The gene is a tumor suppressor gene, and its mutation at the germ-line level means Vivi's body couldn't stop cellular mutations of this type from turning into tumors.

Ultimately, LeBonheur agreed to perform surgery and St. Jude agreed to place Vivienne on their current experimental protocol for ATRT. No matter what the future holds, the generosity and skill of Dr. Frederick Boop at LeBonheur and Dr. Gajjar and his team at St. Jude are miraculous, providing our daughter's best chance at a longer life or the long-shot chance of survival.

brain tumor, tumor sites in the spine, and a massive tumor on the kidney. The involvement of the kidney resulted in a diagnosis of ATRT. We were told survival chances or the hope of significant life extension were non-existent, and that the merciful, humane thing to do would be take Vivienne home on palliative care and say goodbye. We headed to Maine to spend time with family there, and enjoy life as a family while we could.

During that time, we talked, loved Vivi and prayed a lot. Eventually, the decision to pursue palliative care only became very upsetting for us. On our return home, we began to look into treatment options, whether at CHOP or elsewhere. CHOP refused to do

MRI on July 17. We waited for results, expected the next day.

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