

Ellie Kate

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD
HAS NON-KETOTIC HYPERGLYCEMIA (NKH)

My name is Ryan McLaughlin, and I am the proud mother of Elizabeth Kathleen ('Ellie Kate'), who has Non-Ketotic Hyperglycinemia. I have been so thrilled and inspired by your web site! I wanted to share our story with you.

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The world was turned upside-down for us on December 4, 2005, the day our daughter, Ellie Kate, was born. By the looks of things, she was a healthy baby. But that would soon be proven wrong. From birth Ellie Kate had trouble opening her eyes, staying awake, eating, and she had a weak cry. Doctors and nurses thought she was a laid-back baby and was possibly suffering from mild jaundice. During her first week of life, I had her seen by a doctor or nurse every day - I knew something was just not right. But Ellie Kate's standard blood work seemed fine, and the doctors and nurses were not alarmed. By the fourth day of life, Ellie Kate was not eating and would not wake up. That day, December 8th, my husband Michael and I took her to Baptist hospital where doctors prepared to give her an IV and treat her for jaundice. Within ten minutes of being at Baptist, Ellie Kate stopped breathing and her temperature went down to 92 degrees. We knew something was desperately wrong, and doctors immediately rushed Ellie Kate to the PICU and put her on life support. Michael and I were told Ellie Kate would probably not live through the night.

Literally hundreds of tests were run those first several weeks in the hospital. Many things were ruled out and the doctors came to one conclusion - they were dealing with a metabolic/genetic disorder. Ellie Kate lay in a comatose state and continued to be on life support. By December 29th, Doctors at Baptist Hospital decided they had done all that they could do. They were stumped and suggested that Ellie Kate be transferred to a hospital which specialized in metabolic/genetic disorders. Through God's Providence, we chose to be sent to Texas Children's Hospital in Houston, Texas.

On December 30th, Ellie Kate and I were medi-flighted to Houston. Our family (we have a three year old son as well) was separated not only by illness, but by distance as well. Thanks to generous family and friends, Michael and our son Conner were able to fly in on weekends and see us. Doctors worked vigorously to find the cause of Ellie Kate's problems. It was in Houston that Ellie Kate woke from her coma. She also pulled out her ventilation tube, and virtually took herself off life support. I was able to see Ellie Kate's eyes and hear her cry

for the first time since birth.

By the end of the second week, and after several MRI's, MRS's, spinal taps, EKG's, EEG's and many other blood tests, doctors had made a diagnosis - Ellie Kate had a rare genetic disorder called Non-Ketotic Hyperglycinemia (NKH). Ellie Kate continued to get better there in Houston, and she was sent home shortly after her diagnosis.

Since being in Houston, Ellie Kate has been hospitalized several more times in Oklahoma City. In January, she spent two weeks in the hospital (one of those on life support), treating RSV. After being home for a month and a half, Ellie was sent to Baptist Hospital for stomach problems. She had become unable to tolerate any food. She and I stayed in Baptist for two and a half weeks and then were transferred to Children's Hospital. After two and a half weeks of tests, doctors at Children's decided to do exploratory surgery on Ellie Kate's intestines. They found a problem and were able to correct it, allowing Ellie to once again eat and receive nourishment by mouth. Once Ellie proved that she could in fact eat by mouth, she was released from the hospital and sent home on hospice care. This two month stint in the hospital was extremely stressful on the family, who once again was separated. Conner lived with his grandparents while Michael and I lived at the hospital with Ellie Kate.

Now weeks are pretty busy for us. Almost every week Ellie Kate goes in to Children's Hospital for blood work. She also sees Sooner Start therapy (state funded program) every other week, and we were recently released from hospice care. Other days are filled with Neurology appointments, cardiology appointments, and general pediatric health appointments. Though it is busy, one thing is for sure - Michael and I are thrilled that our daughter is at home with her family. Ellie Kate is beating the odds and doing better than doctors expected.

Ellie Kate has a long road ahead of her, but she is a fighter! She suffers from seizures, myclonic jerks, and irregular heartbeat, among other things. She also is behind developmentally, although it is yet to be known what extent of brain damage she has.

Our experience has put a passion in my heart for newborn screening (NBS) - increasing the testing nationwide, and of course here in our home state of Oklahoma. I want to get the word out and let other families know about testing that should be done. It is so very important! If only we had known about Ellie's NKH right after birth - we would have had a diagnosis so much sooner, among many other things!

In fact, increasing NBS in Oklahoma has inspired me to run in the Mrs. Oklahoma Pageant. My platform of course is NBS. I want to learn everything I can about it in order to make a difference here in Oklahoma.

[Editor's note: Ryan McLaughlin was named Mrs. Oklahoma in April, 2007, and participated in the Mrs. United States pageant. She is currently promoting newborn screening with every opportunity made available by her title.]

Thank you for what you are doing! I cannot say that enough. I hope I will be able to make a difference in increasing NBS here in Oklahoma!

Written by Ryan Elizabeth McLaughlin
Updated May 22, 2007
Mother of Ellie Kate (NKH), born December 4, 2005

Visit Ellie Kate's website at www.helpelliekate.com