



Newborn Screening  
Saves Babies  
One Foot  
at a Time

# Ben

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD  
HAS HOMOCYSTINURIA (HCU)

## Ben's Story of Triumph

I remember going down the stairs of our apartment, in labor, to get in the car to go to the hospital. I had been having labor pains for 3 days. The Doctors had tried to stop it, but it apparently wasn't going to work. At the Hospital, at 11:00 a.m. on January 10th, we heard our son's first cries. A beautiful 6lb. 14 oz. boy, born 4 weeks early. His dad and I were overjoyed! He was just perfect. Benjamin had the newborn screening, as all newborns in Georgia do. We took him home on January 12, 1990 and proceeded to do all the things that normal parents do. We were so happy too finally have a child after 5 years of marriage.

When Ben was a little over a week old I got a call from his pediatrician informing us that his newborn screening was abnormal. They proceeded to tell me what Ben had been screened for and fear just gripped my heart I had never heard of these-what I thought was diseases. I called my mother and cried, "Something is wrong with my baby"! The following week, we took Ben to Emory Egleston Children's Hospital where we met Dr. Fernhoff and Barbara Kruse, the nutritionist. (his nutritionist is now Erica @ Emory) He was tested further to determine which disorder he had. When it was determined that Ben had non B6 responsive Homocystinuria, it was explained to us in detail. Ben's body would be unable to break down excessive protein into other amino acids and that in order for him to have a normal life, he would have to be put on a special low protein diet. I was still so afraid.....would my son be mentally challenged, would he walk and talk, would he be normal? We were provided with Hom 1 & Product 80056 to begin making his formula. I look back now at the first time I mixed his formula and I bet it took me an hour!

Ben has been on a low protein diet for almost 12 years now. And I am very happy to say that, thanks to God, Ben's Homocystinuria is in excellent control. He is in the 6th grade (in the gifted student program) and has been a straight A student since he started school. He plays basketball, football and baseball. He's even been chosen for All-stars, in baseball, for the last 2 years. He now has a 2 1/2 year old sister, Breanna. (She does not have Homocystinuria). He does all the things any other 11-year-old does. He spends the night with friends, goes, to parties, eats out, and he's a whiz at video games! He is warm and generous and would give someone the shirt off of his back. He is a GOOD kid!

In closing, I just want to say that Ben is a very exceptional young man. He has taken responsibility for making his own formula and taking his medication. He takes Vitamin B6, Betaine Powder, and Propranolol for migraines. He also keeps track of what he has eaten during the day and how much methionine he has taken in. He does get aggravated sometimes (as we all would) but, 99.9% of the time he just takes it all in stride. He knows what he can and cannot have and he knows how important it is that he drink his formula and stay on his diet.

We are very, very proud of him and the wonderful person that he is.

Written January 2002 by Katrina Massengale.

Mother of Ben, born January 10, 1990