

## Danny Dobbs

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD HAS  
ISOVALERIC ACIDEMIA (IVA)

My name is Sharon and my son, Danny, has Isovaleric Acidemia (IVA). The odd point about Danny's case is that he was not diagnosed until he was 3 years old.

It started with a fever on Sunday, January 27, 2002. My husband took him to the pediatrician on Monday and Danny came home with an antibiotic due to a sinus infection. By Monday night, Danny was throwing up (with drops of blood) every 20 minutes. I called the doctor's exchange and was told that a bad flu was going around and the blood was because of an irritated throat.

After being up with Danny all night, I called the doctor on Tuesday and said that Danny was sleeping an awful lot. Once again, I was told that a bad flu was going around and that sleep was the best thing for him. Danny looked terrible by Tuesday night, but I was too embarrassed to call the doctor again. I told myself that everything would look better in the morning. Thank God I slept with Danny that night. Around 3:00 a.m. he fell out of bed and was extremely disoriented. I couldn't ignore it anymore. My husband and I took Danny to the ER. His skin was "glow-in-the-dark" white. He had dark circles under his eyes and he was unable to wake.



My husband and I thought that we were taking a dehydrated kid to the hospital. At the ER (St. Louis Children's Hospital) two doctors and four nurses raced to help Danny. Initially a doctor said that Danny was a diabetic and that he was in a diabetic coma. But the initial tests didn't confirm this, so we spent the day being bounced between diabetic doctors and genetic doctors. The final test ruled out diabetes, which left us with IVA (along with RSV and Pneumonia).

My husband and I were shocked. There was no history of anything in either family and we had a healthy 4-year-old named Jake. I had what I thought was every prenatal test and an amniocentesis. Danny was a healthy 8 lb., 2 oz. baby. But as I was reading the IVA literature in my son's hospital room, the pieces did fit. Although it was frightening to read the side effects as my son lay speechless in the bed.

With the wonderful care at St. Louis Children's Hospital, Danny was talking again after 2 days, and after 5 (total) days, we were home with a new diet and medications. Danny's Isovaleric Acid level in the hospital was 3511. The most recent IVA level was 4-yes, FOUR!

We are so thankful for the timely care that Danny received. However, with expanded newborn testing, we would not have had to play such a risky gambling game with our son's life.

Sincerely,  
Sharon Dobbs  
Written August 2002 2000 by Sharon Dobbs  
Mother of Danny, IVA  
St. Louis, Missouri