

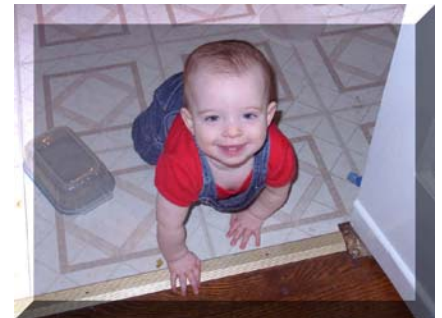


Newborn Screening
Saves Babies
One Foot
at a Time

Tallina "Talli" Renee

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD HAS
PROPIONIC ACIDEMIA (PA)

Early in the morning of October 4, 2001 I got a phone call from our social worker to say that the little girl we had been waiting for had been born. Talli's birthmother had delivered her right after midnight. We made arrangements to pick her up from the hospital in Ephrata, PA on October 6th. While waiting for the social workers to show up, her Birthmom's Bishop came and met us in the lobby in the hospital to tell us that the hospital was keeping Talli another night because she was vomiting, they thought that she had a problem with milk products, so were switching her to soy formula.



After a few hours of waiting we finally got to meet our little angel. She was still vomiting the next day, so the pediatrician at the hospital told us to take her to his office at the end of the next week for a weight check. We took her to our hotel (if an adoption is across state lines you have to wait a few weeks to bring a child to your home) and for 4 days fed her and cleaned up her vomit. We called friends and family and everyone kept telling us that babies spit up all of the time, but we felt like something was wrong. We even started keeping track of how much she ate and when.

On October 10th we got a call from a social worker saying that Talli has Propionic Acidemia, which was detected through expanded newborn testing. He told us that it was not serious or life threatening and to see the pediatrician the next day. After a visit to the pediatrician, my husband spoke with Dr. Morton and he told us to get to Children's Hospital of Philadelphia as soon as we could. I threw some things into a bag while Rawlo spoke with him. Thankfully, Dr. Morton called ChoP and the ER staff was ready for us!

The metabolic physician, Dr. Madan, sat and spoke with us after some initial blood work was done. (She was pretty shocked when she started to do some genetic counseling and we told her Talli was being adopted!) Talli was severely dehydrated and lethargic, but luckily her ammonia level was only 275 when she was admitted. It peaked later that night at 450, but was quickly brought under control with Ucephan. It took several hours to get all of her IVs in and her Central line, and it was so sad to see her like that. She spent 3 ½ weeks at ChoP trying to get just the right diet and get her reflux under control. We had had it by that time and told the doctors that we would try to go it alone at home. The hospital staff was incredible! Dr. Berry and Dr. Madan were terrific and answered all of the questions that we had. Dr. Kelly Wade, neonatology fellow, was great also.

So far now at 17 months old, Talli has had 6 lengthy hospital stays and even more ER visits, with most of them being for IV hydration because of an illness and not for acidosis. She is developmentally delayed in all areas except cognition. She is cautiously taking her first steps, can quickly climb down a flight of stairs and amazes everyone with her ability to climb. Physical therapy and occupational therapies have been difficult at times because Talli can think of alternatives to doing things to compensate for her weak muscles. She loves to eat

(mainly pureed baby food) and is starting to get proficient at using a cup! She is a social child who loves people and animals.

Besides hospitalizations, Talli's growth has been a problem. At birth she was small at 5lbs 10 oz, but she fell further on the growth charts as time went on. She appears to have some undiagnosed immune/allergy disorder that utilizes her protein and calories, instead of her body using them for growth. She also is very susceptible to any illness at all and was getting ill every week, so we decided that it was best for her not to leave the house, except for needed visits to therapists and doctors. That strategy has worked well and she has not been in the hospital for almost three months now (although, I am staying up late writing this because her urine ketone levels are up and we might be going into the hospital tonight.)

Talli has been the joy of our lives! We can't imagine our lives without her as a part of our family and we feel that God made it so she would be in our family. We are so blessed that she was born in Lancaster County, PA where the hospitals screen for so many disorders. If she had been our biological child or born in a different area I feel that she might not have lived since she had such an early onset of the disorder or she would be more severely affected than she is. Her prognosis is good if we can keep her out of crisis and hopefully her only problem will be a restricted diet.

Sincerely,
Brittany & Rawlo Smith
Written March 2003