



Newborn Screening  
Saves Babies  
One Foot  
at a Time

# Margaret

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD  
HAS ARGININOSUCCINIC ACIDURIA (ASA)

Margaret (Maggie) Partlow was born on February 6, 2003. I had a normal pregnancy delivering only a few days late and Maggie was born a "normal" size (7 lbs, 1 oz and 18 3/4 inches long). She is my second child and was breastfed for her first year. Once we started giving her regular foods all she just wanted to eat was bananas. She gradually started trying other foods but did not seem to eat much. Her low weight we (doctors and us) were thinking may have been caused by chronic ear infections starting July 2003 through January 2004 for a total of 8. In January 2004 we had tubes put in both ears and hoped that our little Doodles would gain weight. She started eating everything.

During her 1st birthday party, she started to get real warm. Concerned, I took her temperature to find out that it had risen to 105.8. Her temperature remained high even with doses of Tylenol and Motrin recommended by her pediatrician. Her little heart was beating so fast that I called the doctor back for a 3rd time, where she quickly decided to send us to the hospital. We were admitted for 2 days mainly to rehydrate her and kill an infection believed to be in her blood (she had a cold for several weeks and just couldn't shake it).

On March 26, 2004 she started vomiting repeatedly. The pediatrician said it probably was the stomach flu running rampant BUT my gut told me otherwise. We ended up at the pediatrician office on Saturday & Sunday. We then ended back in the hospital for 2 more days as she kept vomiting. She had no diarrhea so it was determined that it was not the stomach bug. On Tuesday, we ended up at Albany Medical Children's Hospital, which is very good. Albany Med stated that if they could not figure out what was wrong with our little girl, then we would be sent to Boston Children's. We ended up in the PICU for 2 days, to monitor her falling glucose levels, which was due to her refusing to eat. At this point her weight was down to 16lbs and 5 ounces from 17lbs and 12 ounces just a few days earlier. The weight is a concern still and we have been told that if she can not put the weight on herself then a feeding tube will be needed. She currently weighs 19lbs, 6 oz and is 29 1/2 inches long.

They took so much blood from her that anytime the nurses drew more she would bleed from the other holes in her arm. Eventually they had to take blood from either her neck, her groin or her scalp. The blood drawn from her scalp was the SCARIEST thing for me. I NEVER LEFT HER SIDE!!!! I REFUSED TO LEAVE!!! My husband would go to work & take care of our 3 year old daughter Virginia, then drive down to the hospital to be by our side for a few hours. We finally left Albany Med on Friday, April 2. We ended up back on Saturday, April 3rd as she started to vomit again and stayed until Sunday, April 4. We went for more test including an upper GI scan and a CAT scan of her little body. She was reluctant to eat because whenever she did she would vomit, so we assume she thought it was easier not to eat or drink.

We ended up back at Albany Med Wednesday, April 7 until Saturday April 10. We were home for Easter and very happy to be home. By this time we were on a first name basis with most of the staff in Albany Med.. The Geneticist got a lot of the results back and didn't see anything abnormal except her homocystein levels. He took more blood and reran some of the tests at Mt. Sinai Hospital in NYC. He actually went down to see the tests and look first hand as he suspected something with her proteins.

On, Tuesday May 4, we took her to the allergist to find out she is highly/deathly allergic to eggs. On Wednesday, May 5, we found out about the ASA from the Geneticist. We are thankful and fortunate that she has a mild variation of ASA, you can't tell by looking at Maggie she is sick.

Maggie was again in the hospital January 15, 2005 for a few days.

We go for monthly weight checks to our peditirican and quarterly visits to Dr Adams, gentics. We are set up on the Green Light Program with Cambrooke Foods which has been wonderful in helping manage Maggie's condition.

We would like to extend a SPECIAL thank you to Dr. Gayle Buckley & staff, Dr. Darius Adams & staff, family, friends and the Corpus Christi community.

Written June 2005 by Lisa Partlow

Mother of:

Maggie - ASA

Virginia, age 4, unaffected