



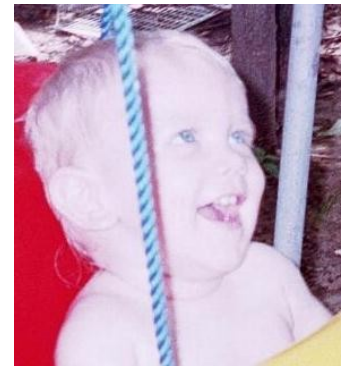
Newborn Screening  
Saves Babies  
One Foot  
at a Time

## Josias

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD HAS  
GLUTARIC ACIDEMIA TYPE I (GA-I)

Joey's conception was deliberate, a Valentine's Day gift to each other. Joey's father and I really wanted a son. So, we were overjoyed to learn that our single attempt succeeded and by mid March of 1998 we knew we were pregnant.

In my prayer life, I sensed I would have a son, and that his name should be Josias. I looked in the bible and read the story of Josiah and found that the bible figure had been responsible for restoring true worship in the house of God. I knew that somehow, in some way Josias would do the same. There was to be much heartbreak and a lot of changes before discovering what I feel the plan of Joey's destiny would achieve.



In the first 6 months of life Joey grew and developed normally. His pediatric visits were smooth and complimentary; our hearts were filled with adoration. We were a happy family, his sister, Mercy, loved him with all her heart and we anticipated father/son wrestling matches, football games and all the strength and energy health brings.

By 6 months we saw that he was not quite as energetic or ambitious as other babies his age. Looking back I see it much clearer of course, but through raising my daughter and the brief time before we realized Joey was ill, we were told not to worry, and that children develop differently. I was determined not to hold Josias against his sister or compare him competitively to other children. In July of 1999 though we were slapped in the face with the facts. This is the reason I advocate newborn screening so strongly.

No parent or loving relative should ever have to feel the immense heartache and confusion we have felt. After a brief cold Joey was taken to our family doctor. He lifted Joey by the arms and told me something was seriously wrong with him. I was completely shocked and amazed even skeptical as our doctor gravely instructed me to run, not walk to Children's Medical Center and have him examined there.

We did as we were told, fighting to keep our heads together, but all sense of peace and hope was destroyed when we entered the exam room. I have personally never seen doctors so intense. Soon they were running every test, taking samples of every fluid including a spinal tap. I was lost in the flurry of motherly feelings, confusion and the dance of the doctors and nurses. Baffled at how something so evidently serious could occur without my knowledge. But it was happening.

Over the next week the truth unraveled. Joey worsened and went on a short cycle of seizing, gagging or vomiting then sleeping. He was lethargic and noticeably distant. When the results from the MRI came back it showed considerable brain damage. Joey lost his suck and feedings for the first time became a concern. At the

end of our hellish week I was told that Joey would be sent home AND I shook with fear at the prospect of taking him home not knowing why he was sick, what the cause was or how to care for him. Luckily, after pacing the floor for about 15 minutes, the metabolic team entered the room and announced that they had a diagnosis and that we would be staying until I was trained and he was stable.

The rest of the news was terrifying to say the least and much of it fell on the cushioned ears of a heartbroken mother. I was concentrating on the good news, of a found cause. A found cause meant a plan of care, plan of care meant recovery. I thought, I hoped.

The month to follow was shaky and painful. He required a NG tube before his discharge and in October had to have a g-button placed. Everything happened so quickly, it made the choppy waters flood the shores.

I wish I could say that everything was perfect, that we made no mistakes. I wish I could say our married life was not adversely affected or that everyone immediately accepted Joey and his condition and I wish I could say that everyone understands, but. I can't.

I can say though that Joey's existence brought out a patience, hope, peace and true love.kindness, generosity and strength I never knew existed in me and many of his loving relatives. And in this way so far has fulfilled the hint I was given of Josias' destiny and resembles the name he bears.

Thanks you all for reading. May we all be blessed with the focus and strength to achieve peace.

With all my heart,  
Tiffany Wilson  
Written March 2001 by Tiffany Wilson  
Mother of:  
Josias, born November 19, 1998  
Mercy, born October 10, 1996