

Noah

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHO LOST A CHILD TO
TRIFUNCTIONAL PROTEIN DEFICIENCY (TFP)

Our precious son Noah passed away on March 23, 2004 at 10:21 pm after a long fight for life. Noah was admitted to Wolfson Children's Hospital of Jacksonville Florida on February 13th, 2004. That Friday started out as a normal day. My husband William and I got the boys ready to go to the local store. Before we left I fed Noah, it was around 6:30 am. Noah had a Metabolic Disorder called Tri-Functional Protein Deficiency. It was very important for us to feed him every three hours no matter what. During that feeding Noah was his normal self. He took most of his feeding and he was very alert. He seemed fine during our trip to the store. As I was placing Noah and his car seat back into the car I noticed his skin coloring. He was very pale and his skin was blotchy and very cold to the touch. And he started moaning while his eyes fluttered. I knew something was wrong.



The two previous weeks we had two false alarms with Noah. My first son Caleb died from TFP at the age of fourteen days. He went undiagnosed so I have never raised a TFP child before. Our geneticist told me to bring Noah in if I felt that he was acting differently or if I felt he was becoming ill. So we did have two previous trips to the doctors but everything turned out to be okay. Well that day there was something wrong. We rushed Noah to the hospital. On our way there I did call our doctor to inform him that we were taking Noah to the hospital. He then in turn notified the hospital of Noah's case and what the protocol was for his disorder.

William dropped off Noah and I at the ER entrance. William had to take our other son, Caden, to the babysitter. We knew we would be at the hospital for a long time. As soon as I walked in I told the staff who I was and what was going on. I also informed them that our doctor called them to tell them that we were on our way. I also handed them a copy of the protocol letter. I was ignored. I was told to sign in and please take a seat. Well I didn't take a seat. I stood in front of the desk stomping my foot. Finally after a few minutes the lady behind the desk took a look at Noah. She rushed us in back. Once we were in the actual ER Noah's breathing and heart stopped. I watched them work on Noah for almost an hour before he was stable enough to be moved to the PICU floor. My son went through hell that day. He survived! It was not his time to go.

Noah hung on for five and a half weeks. I was so blessed to have witnessed his first real smile a few days before he passed away. During the finally weeks of Noah's life William and I were on an emotional roller coaster ride. We classified our days as a good or bad day for Noah. We truly felt that Noah was going to pull through. When I would visit Noah I would often read healing scriptures to him and play CD's for him. Noah loved listening to music. During this time I read the book Charlotte's Web to him. I had an eerie feeling that once I finished the book Noah would pass away. So for a few days there I didn't read it to him. Instead I read from the Bible. But three days before he passed away I started reading it to him again. I finished it the day before he passed away. I will cherish that book forever.

On his last day of life he was started on a new study/protocol. We were hopeful that it would help with his heart function. We will never know if it would have worked. Noah's heart was too weak from a second crisis that he had during his second week in the hospital. He ended up with cardiomyopathy. Noah's little body couldn't take anymore. During his final week of life he ended up with two chest tubes, one upper lobe lung collapse and a bacterial infection.

When I arrived that night, I greeted Noah with a kiss on his forehead. That is when I noticed how pale and cold he was. He reminded me of Caleb the day he passed away. For the first hour of my visit he didn't open his eyes like he usually would once he heard my voice. I sat down in the chair next to his crib and started praying and reading healing scriptures while I played a CD with healing scriptures. Around 9:30 pm my friend Angel and her husband Eddie arrived. I just met Angel the week before and I met Eddie that night. All three of us went to Noah's bedside. Once there, Noah opened his eyes and squeezed mine and Angel's fingers for about ten minutes. Then Noah closed his eyes and all the alarms went off. The staff worked on Noah for twenty minutes. They were about to take extreme measures. That is when I found my voice and told them to let Noah be with God and his big brother Caleb. My son was gone the moment he closed his eyes.

William, Caden, and our close friends soon arrived. We all spent the next four hours holding and loving Noah. We have all learned so much from Noah. Noah has personally given me so much. I now have closure with Caleb's passing...I was haunted by his passing for two and a half years. I was always thinking what if he would have been tested at birth...what if we would have placed him on a low fat diet. I now know that nothing could have been done for him. We did everything medically for Noah. The standard protocol does not work for the type of TFP my sons had. However it did prolong Noah's life for four months. For that I am grateful. We were able to have Noah at home with us for two months. I will cherish those four months forever. I love and miss you BIGGIE much Noah.

Sincerely,
Shelly Grabow

Written July 2004 by Shelley Grabow
boo1974bear@netzero.com

Mother of:
Caleb Patrick 9/14/01- 9/27/01 ~ TFP C527G
Caden Nathaniel 12-31-02 Multicystic Dysplastic Kidney Disease
Noah Riley 11/18/03-3/23/04 ~ TFP C527G