



# Talon's Story

BBAF ANGELS  
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by Angel Den Mom Laura

Talon was born January 24, 2006. He was full term and weighed 7lbs 14.9oz and was 20 3/4in. About a week after bringing Talon home from the hospital, his mother Tiffany began to feel like there was something going on in his tiny body that just was not right. She had no idea what the next 3 1/2 years had in store for Talon and her family.

Talon was an extremely fussy infant who on some days would scream and cry for over 12 hours. At two weeks of age his pediatrician prescribed Zantac and assured his family that he just had reflux and would be fine. Tiffany was not comfortable giving him Zantac and can still remember the face he would make every time she gave it to him. On the medication, he continued to scream and fuss and began projectile vomiting every time he nursed. Tiffany became housebound and had no visitors. She addressed these issues at every well baby check and the pediatrician never expressed any concern. The family got used to the chaos and chronic vomiting-- life went on.

When Talon was a year old, he had cow's milk for the first time. He vomited within minutes. Tiffany discussed this with his pediatrician and was told to keep trying and he would grow out of it. She continued to give him milk but, in addition to the vomiting, he developed diarrhea. It was at this point that Talon's diagnostic odyssey began.

The first of three GI doctors they visited ordered countless tests and he underwent his first endoscopy. The endos-

copy showed that his lower esophageal sphincter did not close and his biopsy was normal. Testing for allergies, parasites, diabetes and lead all came back normal. Talon continued to get sick on what appeared to be a monthly cycle. On December 14, 2008, Tiffany scheduled an appointment with a new GI doctor as the first one had retired. The new GI did not feel like it was necessary to run further tests. Talon had another episode on January 24, 2009 which Tiffany addressed with the pediatrician at his well baby checkup on January 27th. He suggested taking Talon back to his new GI doctor. Given the frequent doctor appointments, Tiffany started to feel like everyone thought she was crazy. She was worried that people thought she was crazy as nobody had seen him when he was sick and all the obvious things they were testing for were coming back 'normal'.

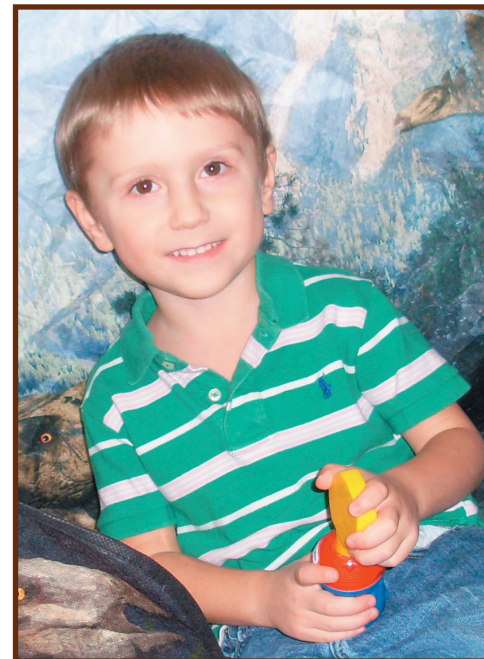
On February 11, 2009 Talon got sick again, and this time he was throwing up blood. Tiffany immediately took him to the ER and the doctors ran further tests. He was given an IV and he was discharged with instructions to follow up with his doctors. Tiffany took Talon back to his pediatrician and again they were told to go back to his GI. At the next visit the GI doctor ordered a head CT, kidney ultrasound, and x-rays. She also wanted to do another endoscopy.

On March 10, 2009, the day he was having his head CT, Talon began dry heaving. The scan was completed and there

were no other incidents. On March 11, 2009, he had the second round of testing done. Those also were without incident and all came back normal.

On March 18, 2009, Talon was scheduled for his second endoscopy. On the way he began vomiting in the car. At the time, Tiffany thought he would be alright but mentioned the vomiting to the nurse. He became increasingly irritable and by the time they got up to the waiting area he had begun vomiting again. The doctors didn't feel comfortable going through with his procedure and instead admitted him. They began an IV and Zofran for vomiting.

Talon stayed in the hospital and the doctors ran more tests. The doctor kept Tiffany updated on the results and he was comfortable with the diagnosis of "Cyclic Vomiting". The last tests they wanted to run were just to 'rule out' any of the more rare metabolic disorders but they assured her that they expected the tests to be negative. Talon was discharged from the hospital and his family waited to hear back from the doctor about test results and rescheduling of the endoscopy. The following Monday was a day Tiffany will never forget. She received a call from the nurse in the GI's office who told her that 'some of the tests for rare metabolic disorders came back abnormal'. Tiffany had no idea what this meant and the nurse did not explain much over the phone. The nurse wanted Talon to come in to the office and they would talk about it more at that time. When Tiffany went to see the GI doctor, the results were



explained but the doctor did not seem concerned or particularly educated about what was going on with Talon. Tiffany made the decision to switch to a new GI doctor.

Talon began seeing his current GI doctor who after looking over all his test results and sitting with Tiffany for almost 2 hours made the decision to refer them to the Biochemical Genetics Department at Seattle Children's Hospital which is where Talon's family finally began getting some answers. They were given an emergency protocol letter, specific instructions and orders for labs. The next time Talon became ill, Tiffany was instructed to take him directly to the ER and give them the protocol letter and instructions.

Over the summer Talon had begun seeing an Endocrinologist. More tests from that end. Further tests were run which seemed to raise more questions rather than give the answers they were desperately seeking.

Talon's next episode was October 19, 2009. He began vomiting early in the morning and with orders in hand, Tiffany rushed Talon to the ER. Although this was not the worst episode he'd had, Tiffany had a feeling that she was about to get to the bottom of what was going on.

Tiffany got a call about two weeks later from Talon's Endocrinologist who stated that Talon should be taken back to the Geneticist. She reviewed the test results with the Geneticist over the phone. The

results initially indicated that Talon had Very long-chain acyl-coenzyme A dehydrogenase (VLCAD) but the Geneticist assured her that he was certain Talon did not have VLCAD, but felt he had Ketone Utilization Disorder (KUD), also known as Beta-ketothiolase Deficiency. Tiffany was told that Talon seemed to be on the more "mild end of it" therefore, as long as they stay on top of his diet and meds, he should continue to thrive and do wonderfully!

Tiffany feels that education is very important, and strives to educate the medical professionals she comes in to contact with about KUD, and other Organic Acidemias. Greater knowledge and understanding in the medical community could have led to Talon receiving his diagnosis many years ago, and Tiffany hopes that raising awareness can help make a difference for another child and family.

Tiffany and her family are still learning about KUD, and what it means for Talon, but she has already become an active, supportive member of the BBAF family. Tiffany is very grateful to have found this foundation, and is comforted knowing that there are other families out there that understand and can relate to her feelings and answer her questions.