



Xander was diagnosed with MSUD at 4 days of life. We were in a hospital that did not know how to treat, was not prepared to treat, and mistreated the disease. At 11 days of life, the geneticist finally reached out to her colleagues who told her that he needed to be transferred to another hospital who knew how to treat him and could at least run labs in-house (we were waiting days for results, which caused Xander to become unresponsive). When we were transferred to Cincinnati Children's Hospital he received excellent care and was responsive within 24 hours. This is all because the team knew how to treat him and he was receiving the correct formula and supplements. By this time he had lost interest in eating and had to have an ng tube for almost 2 years. It took another year following of intense speech therapy to just learn the motor skills necessary to eat. Xander spent about 6 weeks in the NICU but he started to thrive there. Without the correct medical intervention, I wouldn't have the spunky little boy I have today. We were very fortunate to have the team at Cincinnati Children's Hospital to not only guide us through how to care for such a rare disease but to help us understand his needs and guide us through treatment. They provided excellent resources to help us get the supplements he needed paid for so that he could survive. Without that we would have been in a very hard place to financially provide for him because in addition to the medical food, he also required sometimes weekly clinic visits, hospital stays, weekly blood-work (which was also another \$1,700) to manage his care. Xander has been transplanted and no longer needs medical food but when he did, we spent over \$1,000 a month on medical formula until his out of pocket max was reached. This was for the first year of his life. After that we qualified for Medicaid, which was supposed to cover the cost but due to regulations that we were never told about, the hospital ended up paying for it for us. We were very fortunate in that instance. Thankfully, Xander has been transplanted and no longer needs the formula but the cost of the formula in addition to the risks of the disease are what lead us to transplant.