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SB155 - Senate Public Health & Welfare

We thought it was just the flu. Kids get sick sometimes, right? But our precious 7 year old son just wasn't getting better. He became listless so we rushed him to the ER. The doctor did some tests that showed he was having an adrenal crisis. I remember the fear when he said that he couldn't take care of him, that he would have to be taken to Children's Mercy Hospital. How was that possible? It's just the flu, right? But it wasn't. Even then we didn't know. We nearly lost our son that night but we didn't know why. Over the next few days at Children's Mercy he was stabilized but the doctors were still stumped about the underlying cause. Finally, they ran a test to screen for a disease called adrenoleukodystrophy (ALD). I had never heard of it. It is a rare neurological disease, so it couldn't be that, right? But it was. Our lives were turned upside down when we got the news. We were devastated. But at least we knew.

I'm here to advocate for including ALD in the newborn screening regimen here in Kansas. Our family was taken by surprise and we nearly lost our second grade son because we didn't know. This diagnosis can be overwhelming, but it is better to find out early when it can be monitored. Including it in screening will give new parents a chance to plan and for the best care to be given. Currently, 27 states have already added adrenoleukodystrophy to their newborn screening (<https://aldnewbornscreening.org>). New York was the first in 2013 thanks to the tireless efforts of Elisa Seeger to pass "Aidan's Law", in memory of her son who died without early diagnosis. In our own region Nebraska, Missouri, Oklahoma, and Texas have all added it since 2018. We should too.

Newborn screening for ALD is important because it is a genetically acquired disorder that occurs in approximately 1 in 21,000 boys born each year. Unless there is a known family history for the condition, it will go undetected. When symptoms do occur, usually between the ages of 4 to 10, it is often too late for effective treatment. With newborn screening, boys diagnosed with ALD can be monitored for cerebral progression and receive treatment to give them a better chance at a healthy life. Our son nearly died because we didn't have an early diagnosis. We want better for other families.

Troy and Emily Reimer