

Testimony on Senate Bill 155
Senate Public Health and Welfare Committee – March 3, 2022
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Parent Advocate and Adrenoleukodystrophy Parents

Committee members, Thank you for your time and consideration of this hearing,

My name is Travis McMillan, and this is my wife Deana, we know you have or will hear expert testimony from doctors, scientists, and public health professionals. We are neither. We live this life.

Our journey began 5 and a half years ago shortly after our son, Aaron, had his five-year shots and the flu shot at the same time. After two days of him being lethargic and not eating, we had blood work done and his blood sugar was extremely low. The pediatrician sent us to the ER. While we were in the hospital, Aaron was diagnosed with adrenal insufficiency. The endocrinologist on call diagnosed him by his color as he had an Addisonian tan and then through bloodwork. He had always had a beautiful tan and we just thought it was his skin tone. We later found out that we had just experienced his first crisis. We were in the hospital for four days trying to get his steroid dosage figured out before we were sent home. Our endocrinologist drew more blood to attempt to figure out why he had adrenal insufficiency. She thought it was autoimmune but ran the bloodwork just to be safe. We found out over the phone that Aaron had primary adrenal insufficiency, where his brain sends messages to his adrenal glands, but his adrenal glands don't respond. We also found out that he had adrenoleukodystrophy, or ALD. It's a devastating diagnosis when it's first given to someone.

This was the path we started down. Without proper medical treatment, he could have easily died due to blood sugar crash, low blood pressure, dehydration, or other disease related complications. Once we had that diagnosis, we started the level one worry. How will this affect us? How will this affect him? We now had a diagnosis. It wasn't the one we wanted, but it was the one we received. We then started reading the studies on adrenoleukodystrophy. The studies are not for the weak of heart. Dr Huerta, our endocrinologist on call that night, connected us with our experts, Dr Le Pichon the neurologist, Dr Rizzo, the metabolic geneticist and Jill, the nutritionist. We were also accepted into the Lorenzo's Oil study. Had we been in a rural county or town, Aaron may have died, but because we were in a larger city, we had other resources.

ALD has no known cure in the USA except for a Bone Marrow Transplant which is a last resort. In Europe, gene therapy is available for boys or men who have symptomatic adrenoleukodystrophy or adrenomyeloneuropathy. If we truly care about children, then this test is critical for them and their families. Early detection means that a Bone Marrow Transplant can happen as soon as there is regression diagnosed through an MRI. We were lucky that the pediatric endocrinologist diagnosed adrenal insufficiency first as many families find regression through ALD and by then it is too late for treatment.

The costs of screening after a child is born are unnoticeable compared to the cost of a health crisis and diagnostic journey without screening. Financial burden occurs because of diagnosis, travel to specialists and treatment. Aaron currently has two MRIs per year, blood work on a regular basis; this is in addition to regular checkups. His sister has to have genetic testing for the ALD should she choose to have children. Proper care is necessary for longer life.

Earlier detection of devastating and treatable conditions like ALD leads to more information, which should contribute to better care, and being placed with the correct experts for the child. Having seen our specialists with Aaron, we know this to be true for us. At this time, Aaron is asymptomatic and we haven't had to prepare for a Blood Marrow Transplant with him.

We hope that you have considered our testimony and will consider passing this bill so that the Kansas newborn screening program can grow to add new conditions like ALD to the screening panel and continue to meet the needs of Kansas families . We appreciate that you have taken the time to listen to us. Thank you again for your time.





