

Senator Delores G. Kelley
Chair, Finance
3 East
Annapolis, MD 21401

Senator Brian J. Feldman
Vice Chair, Finance
3 East
Annapolis, MD 21401

Re: Testimony of Susan Sullivan 2/3 at 1:00 p.m.

Madame Chair, my name is Susan Sullivan, and I am a constituent of District 3b. As a representative for the greater Maryland Rare disease community, I thank you for the opportunity to share my testimony today in support of SB242.

My Connection: I am a mother whose son Daniel passed away in 2011 from metachromatic leukodystrophy (MLD), a neurological disease that was curable if detected at birth. I cannot express the pain of knowing that if we had done the right test at the right time, Daniel would be with us today. As science advances, more diseases are becoming like my son's—treatable at birth before irreversible damage is done. Newborn screening for disease like this is our most effective way to ensure that all babies have an equal chance at life.

I ask you to Affirm this Commitment: with passage of SB0242 because Maryland's newborn screening lags behind its potential. Maryland should begin screening for diseases like MLD as soon as they are added to the Recommended Uniform Newborn Screening Panel (RUSP). Maryland's newborn screening efforts trail other states. Adrenoleukodystrophy (ALD) was added to the RUSP in 2016 and, while 25 states and DC all test for the disorder, Maryland does not six years later.

Historical Framing of Testimony: Early detection is critical for many diseases, particularly neurological diseases like my son's. Treatment can only halt the damage to the brain and nervous system. If the disease is diagnosed through the symptoms, it is too late for treatment.

Benefits and Impact of the Recommended Uniform Screening Panel (RUSP) Alignment: Since ALD was added to the RUSP in 2016, an estimated 12 babies have been born in Maryland with the severe version of ALD and have gone undiagnosed. If Maryland had begun screening in 2 years as this bill proposes, eight of those children would have been saved.

Conclusion: Thank you for the opportunity to speak in support of SB0242. Maryland is ranked 5th in the nation in healthcare yet we are trailing in newborn screening. I want us to have a state where other families do not have to experience the pain I did. Maryland has been a leader in rare disease research and I you ask that we become a leader in newborn screening once again. Your statehood should not determine your baby's opportunity for a healthy life.

Susan Sullivan

Cure MLD, parent of a deceased child with a treatable disease.
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