

Hello, my name is Emma Grace. My almost sister-in-law has a rare genetic disease called Krabbe disease. Before learning about her diagnosis, I knew very little about newborn screening or how vital it truly is.

As a young woman who will be marrying into a family that may carry this gene, it gives me tremendous comfort to know that my future child could be screened for diseases that I might not even know exist. Early detection through newborn screening can make an enormous difference—sometimes it is the difference between a child receiving treatment in time or missing a critical window when intervention is most effective.

Because of that, it is absolutely essential that this process happens quickly and efficiently. Any delays, added barriers, or complications in the screening process can be incredibly detrimental. When dealing with serious genetic conditions like Krabbe disease, time is not just important—it is critical. Families depend on these screenings to provide answers as early as possible so that life-saving care can begin without delay.

I also want to share that, as someone learning about this process for the first time, it is difficult for me to understand why there must be additional layers of review before these screenings are approved or implemented in Maryland. While I respect that oversight and careful evaluation are important, when we are talking about diseases that progress rapidly, every additional step can mean lost time for families and for newborns who need help as soon as possible.

Federally, Krabbe disease has already been added to the ++[Recommended Uniform Screening Panel](chatgpt://generic-entity?number=0)++. Knowing that experts at the national level have already evaluated the science and determined that this disease should be included in newborn screening makes it even harder to understand why we feel the need to revisit and re-evaluate it again at the state level. For families facing diseases like this, those extra steps can feel like unnecessary barriers when time is so critical.

For families like mine, newborn screening is not just a medical procedure—it is peace of mind and hope for the future. I strongly urge this panel not to backtrack or complicate this process in any way. Please consider the future generations of children whose health, treatment, and lives may depend on timely and accessible newborn screening.