

Testimony

My name is Benjamin Smith. I served on Maryland's State Advisory Council for Hereditary and Congenital Disorders for eight years. During that time, I had the opportunity to see firsthand how the newborn screening review process works in our state.

While the council is made up of knowledgeable and dedicated individuals, the process itself is extremely slow and often inefficient. Much of the time is spent reviewing and debating conditions that have already undergone an extensive national review through the Recommended Uniform Screening Panel (RUSP). The RUSP brings together national experts who carefully evaluate whether a condition should be included in newborn screening based on clear criteria such as the availability of accurate testing, effective treatment, and improved outcomes when detected early.

Despite that thorough national process, Maryland's system requires the council to essentially repeat much of the same work. Over the years I served, it became clear that the council frequently ends up supporting the addition of conditions that are already on the RUSP. In fact, Maryland has never declined to add a condition that has been placed on the RUSP. The outcome has never really been the question. The real issue is the amount of time it takes to get there. Because of the structure of the state process, reaching that same conclusion can take years.

This issue is not abstract for my family. My daughter has Krabbe disease, a rare and devastating condition where early detection is critical. When Krabbe is identified through newborn screening at birth, there is a narrow window where treatment can dramatically change a child's future. When diagnosis happens later, that opportunity can be lost.

Serving on the council while also being the parent of a child with Krabbe made it impossible to ignore how significant these delays can be. Each year that passes in a slow and repetitive review process is another year where families may miss the chance for early diagnosis and early treatment. Not only does this put children and families at risk, it also creates unnecessary legal exposure for the state, as delays in implementing widely recognized screening recommendations could reasonably lead to civil liability.

The purpose of the council should be to help bring new newborn screenings to fruition as quickly and responsibly as possible. With the understanding that Maryland has always ultimately adopted RUSP recommendations, the focus should not be on whether a condition will be added, but on how the state can implement that screening as efficiently and quickly as possible once it has been recommended.

After eight years on the State Advisory Council for Hereditary and Congenital Disorders, it became clear to me that the process often leads to the same decisions that the RUSP has already made—just much later. For conditions where time matters as much as it does with newborn screening, those delays can have very real and lasting consequences for children and their families.