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Written Testimony in Opposition to House Bill 1625
Public Health – Newborn Screening Program – Fees and Core Conditions

Dear House Health Committee Members,

My name is Kathleen Smith, and I am the mother of a 14-year-old daughter living with Krabbe Disease.

When my daughter was born, the state of New York was already screening newborns for this devastating disease. If my daughter had been born there, she would have been tested shortly after birth. Early detection could have allowed her to receive a life-saving treatment before symptoms began. Children who receive treatment early can grow up to live active, typical lives.

Instead, my daughter was born in Maryland, which did not screen for Krabbe disease at that time. Because of that missed opportunity, the disease progressed before we even knew it was there. Today, my daughter is wheelchair-bound, cannot speak, and cannot hold up her own head.

She is a beautiful, joyful child who brings light into our family every day. But I also live with the painful reality that her life could have been very different if newborn screening had been available when she was born.

Our family spent **over ten years advocating** for Krabbe disease to be added to Maryland's newborn screening panel. During that time, we witnessed firsthand how the state's newborn screening advisory committee functioned—and how often it failed to function.

Meetings were frequently canceled because there were not enough members present to form a quorum. Months/years would pass with no progress at all. Families and physicians took time to prepare testimony, only to see discussions delayed or cut short. In one

instance, a physician calling in to explain the medical urgency of screening was repeatedly spoken over and not given the opportunity to fully present critical information.

These delays have real consequences. Every year that screening is delayed means more children who could lose the chance for early treatment.

Maryland should not be re-litigating decisions that have already been carefully evaluated at the federal level through the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) and the national Recommended Uniform Screening Panel (RUSP). These recommendations are based on extensive scientific review, expert consensus, and years of evidence.

Creating additional layers of state bureaucracy only slows the adoption of life-saving tests. Looking at Maryland's record, there were years where no new conditions were added to the newborn screening panel at all. During those years, children were born without access to screenings that were already being used elsewhere in the country.

Newborn screening should move **as quickly as science and evidence allow**, because every delay can mean the difference between a healthy child and a lifetime of severe disability.

Maryland families deserve a system that responds quickly to proven medical advances. The current committee structure has repeatedly slowed progress instead of facilitating it.

For the sake of future children and families, Maryland should adopt a streamlined process that automatically aligns our newborn screening panel with federal recommendations, without unnecessary delays.

No family should have to spend twelve years fighting for a test that could save a child's future.