

TODD B. MORGAN
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Calvert and St. Mary's Counties

Environment and Transportation
Committee



The Maryland House of Delegates
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THE MARYLAND HOUSE OF DELEGATES
ANNAPOLIS, MARYLAND 21401

February 5, 2024

The Honorable Joselyn Pena-Melnyk
Chair, House Health and Government Operations Committee
241 Lowe House Office Building
Annapolis, MD 21401

RE: HB096 - Health - Newborn Screening Program - Krabbe Leukodystrophy

Dear Chair Pena-Melnyk:

The purpose of HB096 – Health – Newborn Screening Program – Krabbe Luekodystrophy is to add the disorder to the list of diseases screened by the Newborn Screening Program. Krabbe Disease is a neurological disease caused by the absence of an enzyme which leads to the loss of myelin causing the nerves and brain to be unable to communicate. Symptoms begin mildly around 4-6 months of age but quickly progress to blindness, deafness, seizures, decreased mobility and eventually death. Early detection of Infantile Krabbe Disease allows for a transplant which can dramatically improve the quality and longevity of the child's life. However, this operation can only be done before the child is 6 months of age. Most often by the time the child is diagnosed it is too late to do the transplant.

For many years Krabbe Disease has been reviewed and discussed in legislative and medical circles to determine if testing infants for the presence of Krabbe Disease at birth would be beneficial. On January 30, 2024, the Advisory Committee on Heritable Disorders in Newborns and Children recommended to the United States Secretary of Health that Infantile Krabbe Disease (IKD) be added to the Recommended Uniform Screening Panel (RUSP). The addition will encourage many states to include IKD among those diseases evaluated. I have drafted an amendment to this bill which will limit the of the phase disease to only the Infantile Krabbe Disease in keeping with the federal recommendation.

Although listed in the RUSP, each state decides which diseases to add to their Newborn Screening Program and which to leave off. At this time, fifteen (15) states test for Krabbe Disease. Maryland is not one of them. For many years, advocates and legislators have asked the Maryland State Advisory Council for Hereditary and Congenital Disorders to consider adding Krabbe Disease and Infantile Krabbe Disease to the state's Newborn Screening Panel but have been unsuccessful.

Although Maryland will now be required to consider the inclusion of IKD to the Newborn Screening Panel, the Advisory Council can decide not to add the disease. It is our intention to have Infantile Krabbe Disease added to the list without years of continued push back. Without early testing, the window to

change a child's life through a transplant is missed. Maryland families need to have every chance to raise their children with the best available health care. Let us give it to them.

Thank you for considering this bill. I ask for a favorable report from the committee.

Sincerely,

A handwritten signature in black ink that reads "Todd B. Morgan". The signature is written in a cursive style with a large, stylized 'T' and 'M'.

Todd B. Morgan
Delegate, Calvert/St. Mary's Counties (29C)