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Budget & Taxation Committee



THE SENATE OF MARYLAND
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Senate Bill 117 – Health - Newborn Screening Program – Implementation of Testing

Dear Chair Pena-Melnyk and Members of the Committee,

I am writing to introduce Senate Bill 117. I know that this Committee has previously heard the cross-file of this legislation, House Bill 96, and that you are aware of the importance of screening newborns for infantile Krabbe disease. Therefore, I would like to take this opportunity to discuss the Senate's amendments to this bill.

This bill no longer adds infantile Krabbe disease to the newborn screening provisions in the Annotated Code of Maryland. Rather, it requires the Maryland Department of Health to add a disease to the State's newborn screening system within one year and six months of the federal Secretary of Health and Human Services adding it to the Recommended Uniform Screening Panel. This removes the duplicative process of approval by the State Advisory Council on Hereditary and Congenital Disorders. Further, given the long-standing interest in testing for infantile Krabbe disease, there is uncodified language requiring testing within one year of its addition to the RUSP.

After discussions following the Senate bill hearing, it does not appear that there is a need for a second approval from the State Advisory Council. At present, this only seems to have the effect of delaying the process further and putting more children's lives at risk. This is particularly true when we consider that, by the Council's most recent communication on this issue, they are struggling to make quorum. We are all aware of the difficulties that many of our volunteer boards and commissions are experiencing with finding and retaining members. This is not so much of a problem for a Commission that is purely advisory, but the current process has in practice has this Council serving as the sole decider of this public policy decision.

Senate Bill 117 rebalances this process so that the Advisory Council is doing just that – advising MDH on how to implement the tests recommended in the RUSP, as well as considering any additional diseases outside of the RUSP for the Maryland newborn screening program. This bill will also avoid the need for future legislation for other diseases; all stakeholders will know exactly what to expect from the State after a federal recommendation is made. This bill provides structure and predictability to a process that has been the source of controversy for at least the last decade.

This legislation was originally intended to limit regulatory delays in implementing life-saving screening for a rare disease. Senate Bill 117 will now not only address this one disease, but all diseases recommended in the RUSP going forward. This emergency bill passed the Senate 45-0. I respectfully request a favorable report on Senate Bill 117. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "J. Bailey", written over a light blue horizontal line.

Senator Jack Bailey