House Bill 96
Opposed

5121 Rondel PL
Columbia MD 21044
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Opposition to House Bill 96

Dear Legislators,

I write to share my opposition to this proposed legislation - House Bill 96. As a parent of a son with a genetic disorder, I understand and respect the motivations of those advocates who have been able to get this legislation put forward. I too have been a strong advocate for the disorder that my son has. I have met with legislators and staff at the federal level with my son on my lap and shared about unmet needs, about how legislators could help. It is moving and powerful to tell our stories. And I sympathize with the advocates behind this legislation, as there is no doubt Krabbe is a serious life-threatening condition.

In my opinion, this legislation is unwise for 2 reasons. The first is that imposing a disease onto the Maryland Newborn Screening list via legislation may satisfy one stakeholder but ignores the other stakeholders involved. It bypasses the process Maryland has had in place for decades to make and implement these decisions, which are often very nuanced. Bypassing the input of the Maryland State Advisory Council on Hereditary and Congenital Disorders (MSACHCD) and the Maryland Department of Health and its Secretary, eliminates the input of experts who have been formally responsible for the newborn screening list and establishing protocols for processing results and follow-ups. This action also has the effect of ignoring the stakeholders who represent individuals who are impacted by the decision to test or not test for a disorder. This legislation ignores the fact that adding a disorder to the list has consequences and is a bad precedent.

Those unaddressed consequences of the legislation are my second reason I do not support this legislation. As a parent, I totally understand why advocates want to include Krabbe. But testing for Krabbe (unless restricted to infantile Krabbe) will identify a smaller number of false positives and those families deserve to be considered in this discussion. They will require more diagnostic tests to confirm or disprove the result.

Currently, the diagnostic path for many of these children is a "high risk" path. These children will require periodic spinal taps (a serious test by itself) and periodic re-examination. This period of diagnostic uncertainty can last a long time and has costs to families, both financial and emotional. Is their child sick or not? (I'm not addressing how or who pays for these additional tests.) It is likely that most, if not all, of these children will end up being diagnosed not to have Krabbe. While that is good news, it was a very hard journey on them to get there. Imposing Krabbe onto the newborn screening list by legislation cuts off the input and evaluation of these consequences by the MSACHCD.

That diagnostic journey for those tested for Krabbe and being a false positive is a real

consequence and the potential impact on these children and their families is significant. I presume no one was aware of such consequences when writing this legislation. But such ignorance of consequences is the problem with placing diseases onto the Maryland Newborn screening list via legislation and bypassing the MSACHCD.

Some might say finding even 1 Krabbe child is worth the impact inflicted upon these other families, but while my heart agrees, I cannot agree. If all that was required of such families was low risk, such as periodic blood tests, or some non-invasive testing, I'd wholeheartedly agree. If we were limiting this legislation to infantile Krabbe, I'd agree, as there is minimal false positives and the impact is much lower. But testing for Krabbe (again, unless restricted to infantile Krabbe), I believe the impact on these other families deserves to be considered and, in my opinion, the risk to those children outweighs the value of providing the test. Their resulting diagnostic journey is a consequence of testing for Krabbe and must be considered in evaluating the value of this legislation. And in my opinion, it fails.

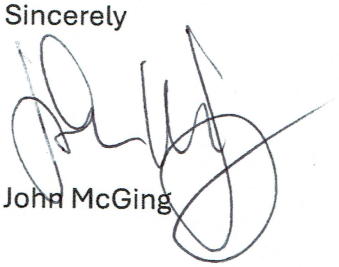
You should also have been notified that on January 30, 2024, the Federal Health Resources Services Administration's Advisory Committee on Heritable Disorders in Newborns and Children voted to add early infantile Krabbe Disease to the Recommended Uniform Screening Panel (RUSP). Assuming that the Secretary of Health and Human Services adopts this recommendation, which is a very reasonable expectation, by law Maryland will require the MSACHCD to review adding infantile Krabbe to the Maryland newborn screening list or explain why it should not be. So in all likelihood, infantile Krabbe will be on the Maryland Newborn screen list withing a year or so. But I have to note this legislation isn't restricted to infantile Krabbe.

I hoped that this activity at the federal level might moot the need for this legislation, but as written, this legislation does not restrict itself to infantile Krabbe, but simply to Krabbe, and so, if implemented, it would still have a negative impact on those false positive families whose diagnostic path remains high risk.

I understand others will look at this and have other opinions, and I respect that. But legislation placing a disease on the list must consider all the stakeholders involved, which in this case will include the Maryland families who will be sent on a high-risk diagnostic journey as a direct consequence of that action. I raise my voice in support of them.

Thank you for your time and attention.

Sincerely



John McGing