

March of Dimes Foundation

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Dear Representative Cruz:

On behalf of the March of Dimes Pennsylvania, I write to express our strong support of HB 1081, which would establish a Newborn Screening fee in Pennsylvania.

The mission of the March of Dimes is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality.

In 2003, the Federal Advisory Committee on Heritable Disorders in Newborns and Children was established to advise the Secretary of the U.S. Department of Health and Human Services regarding newborn screening tests, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In carrying out this duty, the Advisory Committee established the Recommended Uniform Screening Panel (RUSP), recommending 34 conditions for which all newborns are recommended to be screened. To be added to the RUSP, a condition must meet the following criteria: 1) testing for the condition is scientifically sound; 2) treatment for the condition is available; and 3) early detection of the condition would make a difference in the treatment of a patient. The March of Dimes recommends that when conditions are added to the RUSP only then should they be added to state newborn screening panels.

As you likely know, each state operates its own NBS program. In Pennsylvania, a process has been established to allow for proposed conditions to be examined by a panel of clinical experts - the Newborn Screening and Follow-up Technical Advisory Board (NBSTAB) chaired by Jerry Vockley, M.D., Ph.D., Chief of Medical Genetics for Children's Hospital of Pittsburgh of UPMC and representative of clinical experts from all over the Commonwealth. Once the NBSTAB reviews a condition they make a recommendation to the state's Secretary of Health who can then add it to the program based on the advice of the Technical Advisory Board and without the need for legislation. This process is invaluable and the March of Dimes believes the NBSTAB should continue to have the authority to recommend changes to the panel as outlined and restated in HB 1081.

Over the last several years, we have seen legislation be introduced to add conditions that have not been recommended by the NBSTAB in Pennsylvania or the Federal RUSP. These pieces of legislation tend to be unfunded mandates and in the current environment the Newborn Screening Program is not funded at a level that is adequate to test for all of the conditions already required to be screened, and adding new conditions would create additional strain on this already underfunded program.

House Bill 1081 looks to fine tune the process for adding conditions and allowing the critical role and responsibilities of the NBSTAB to remain. House Bill 1081 also addresses the imperative need for a sustainable funding stream for the Newborn Screening Program in Pennsylvania by establishing a Newborn Screening Fee.

Currently, our State Newborn Screening Program is funded through the General Fund. Our Department of Health's dependence on the General Fund for the screening program leaves Pennsylvania's program at the mercy of state budget fluctuations and can limit the number of newborn conditions that can be screened for. Pennsylvania is one of only 3 states in the nation that does not fund their newborn screening program from a fee on each birth. Other states set a fee of \$70 to \$160 per birth, collected by the birthing facility, reimbursed by the insurer, and used to fund their newborn screening program. A stable external funding sources enables a state to expand their panel of screened newborn conditions as technology advances and conditions are recommended by the Federal Advisory Committee on Heritable Disorders in Newborns and Children and the NBSTAB in Pennsylvania.

The March of Dimes believes that instituting a Newborn Screening fee as outlined in HB 1081 allows the Newborn Screening Program to add conditions as they are added to the RUSP and recommended by the NBSTAB and allows more babies to be screened for these life-threatening conditions. We look forward to partnering with Representative Cruz and stakeholders on this great initiative.

Sincerely,



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