American Academy of Pediatrics
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NYS AAP - Chapter 2

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RE: Newborn Screening Saves Lives Act, (HR 2507)

Dear Representative,

As a member of the Legislative Committee of the New York State American Academy of Pediatrics (NYS AAP) - Chapter 2, the Long Island chapter, representing over 1,500 pediatricians across Long Island, I am writing to ask for your support and co-sponsorship for reauthorization of the 2019 Newborn Screening Saves Lives Act (HR 2507). The bill would reauthorize the national newborn screening program last appropriated in 2014.

Second only to the introduction of immunization, newborn screening has seen unparalleled success as a public health program. Newborn screening allows for children shortly after birth to obtain testing for a host of potentially fatal diseases. Early identification of these disorders is critical as treatment early in life – usually by modifying the diet and/or receiving vigilant medical care – preventing death and the need for prolonged, expensive hospitalization.

For example, since galactosemia (a disease which is treated simply by avoiding certain types of sugars) was added to the newborn screening panel, over 2,500 patients with the disease have been identified and spared the life-long mental retardation and neurologic problems which would have otherwise accompanied the disease (1).

As pediatricians, we frequently have to discuss the results of newborn screening with parents. Almost weekly, we have the ability to notify them of results which, if treated now, will have no or minimal impact on their infant. These results include diseases which impact thyroid hormone, which if untreated can also lead to life-long mental retardation, and conditions like sickle-cell disease, where early treatment with cost-effective medications has greatly benefitted those with the illness, reducing morbidity and mortality.

The benefits to America's babies from this program are clear. Since the last Newborn Screening Reauthorization Act, the majority of states have taken advantage of the incentives in the bill. Further, recommendations from the Advisory Committee on Heritable Disorders in Newborns and Children (which the act supports), have greatly expanded the panel of diseases for which we can intervene.

Prior to 2008, when the original Newborn Screening Saves Lives Act was passed, only 10 states screened for diseases on the recommended universal newborn screening panel. Since the program was created, 49 states and the District of Columbia screen for at least 88% of the 34 currently recommended core conditions.

Furthermore, constant funding via the newborn screening program has allowed for the development of a central database of newborn screening information which can aid physicians and parents when a baby is diagnosed with one of these rare conditions and may someday prove to be a vital public health research tool.

Developments in technology over the course of the program have dramatically improved child health by allowing screening for an increased number of potentially incapacitating diseases. In 2014, screening was recommended for 29 of 31 core conditions (2). Over the past 4 years, the committee has increased the Recommended Universal Screening Panel to include 60 different diseases (34 core conditions and 26 secondary diseases).

Funding contained within the 2014 Newborn Screening Bill directly translated to increased access to screening for more infants. Currently, most states now screen for 40-45 disorders (3, 4). Recent additions to the universal screening panel include diseases which impact the immune system and otherwise cause death from overwhelming infections, and spinal muscle atrophy, a neurologic condition causing progressive muscle weakness, profound disability and premature death.

In the future, we hope subsequent versions of this reauthorization will create mandates for all states to screen for the entire Recommended Universal Screening Panel, so that no child will experience a delay in diagnoses and its medically devastating consequences simply due to which state they are born in.

We also hope future versions of the bill will include specific funds to major neonatal intensive care units and public health departments who are charged by the state with administering the program, including follow-up screening results with parents even after they have left the medical facility. Locating parents and arranging an appropriate referral for them to obtain confirmatory testing is administratively burdensome and could be easily relieved with improved funding directly to the hospital units who perform these crucial aspects of Newborn Screening.

Lastly, the Reauthorization will ensure continued National Institutes of Health funding to best understand the impact of continued newborn screening, the potential applicability for use in other disease states, as well as a better understanding of these rare disorders. As rapid advancements in technology allow us to enter a new age of newborn screening, where the potential exists to screen for genetic conditions which may manifest only in older patients, it is imperative that funding be directed toward research activities to maximize the utility of this resource with sensitivity to these future issues.

Sincerely,

Shetal I. Shah, MD, FAAP
President, NYS AAP - Chapter 2

1. Pyhtila, B. M., Shaw, K. A., Neumann, S. E., & Fridovich-Keil, J. L. (2015). Newborn screening for galactosemia in the United States: Looking back, looking around, and looking ahead. *JIMD Reports, 15,* 79–93. Retrieved Aril 6, 2017, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4413015/

2. March of Dimes, Summary of 2014 Newborn Screening Saves Lives Act. Available at: https://www.marchofdimes.org/advocacy/newborn-screening-saves-lives-reauthorization-act.aspx Accessed 5/17/19

3. National Newborn Screening Clearinghouse. Baby's First Test. Available at: https://www.babysfirsttest.org/newborn-screening/the-recommended-uniform-screening-panel Accessed 5/18/19

4. United States Health Resources Services Administration. Recommended Universal Newborn Screening Panel. Available at: https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/rusp/rusp-uniform-screening-panel.pdf Accessed 5/17/19