California Leadership Education In Neurodevelopmental and Related Disabilities

Children's Hospital LOS ANGELES

USC University of Southern California

Amanda Allen (Nutrition), Timothy Bernstrom (SLP), Michelle Joaquin (Psychology), Theodore Mitchell (Nutrition), Rhea Wagle (Psychology)

Reauthorizing the Newborn Screening Act: A Policy Brief

Introduction

In the United States (U.S.), newborn screenings are currently recommended by the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) as a means of saving lives, optimizing childhood development, and enhancing quality of life for children born with genetic conditions. The Hunter Kelly Research program at the NIH advocates for newborn screening and conducts research on potential conditions to be screened for, as well as best practice for testing methods. The CDC operates surveillance programs to track the incidence and prevalence of genetic conditions, and recommends best practices for their prevention, intervention, and treatment. For these programs to be funded and operate across all states, the Newborn Screening Saves Lives Reauthorization Act of 2021 (H.R. 482) must be passed.

Background

Newborn screening (NBS), which began nearly 60 years ago, allows newborn infants to receive a blood test which identifies currently recommended genetic, metabolic, hormonal, or functional conditions which may not be detected until birth or several months or years after birth. Though the Health Resources and Services Administration (HRSA) recommends screening for 35 specific conditions, these recommendations are meant for guidance and the number and types of conditions may vary by state. These conditions may not show symptoms immediately, though many will result in permanent disability, developmental delay, or death without early intervention. NBS also provides states with assistance in developing follow-up and tracking programs for families whose newborns are diagnosed with one of these conditions. Newborn population screening has allowed approximately 1 in every 300 newborns in the U.S. to be identified with one of these conditions, allowing for early intervention, which has saved several thousand lives and prevented worsened prognoses.

Position

We urge you to vote Yes on H.R. 482, the Newborn Screening Saves Lives Reauthorization Act of 2021. In the U.S., the process of operating NBS programs requires a combination of efforts from both the federal and state governments. Each state is responsible for deciding which conditions to screen for, performing the screenings, collecting data, and identifying and treating infants who test positive for a condition. However, the states cannot successfully run these life-saving programs without the support of the federal government, whose primary responsibility it is to provide funding, technical assistance, and quality improvement. The funding provided by the CDC supports the addition of new conditions to state screening panels and ensures the accuracy of screening test results, while the funding provided by the NIH supports advancement in the field of NBS research, and the

Health Resources and Services Administration (HRSA) conducts programs that establish national recommendations for NBS policy and promotes interstate collaboration on best practices. Voting Yes on H.R. 482 would ensure that funding for these programs is provided to modernize NBS programs on the state and national levels. Not only do these programs save or improve the lives of nearly 13,000 babies each year but, through early detection and treatment, they also save taxpayer money by preventing infants from requiring severe and/or lifelong dependence on the health care system.

Pros and Cons

The benefits of implementing such a policy are significant. Earlier screenings serve as a preventative measure for greater complications that could otherwise be reduced when interventions are received earlier on in a person's life. Therefore, the health benefits would be long-lasting and sustainable. Healthier individuals contribute to a healthier society, reducing taxpayer burdens on healthcare throughout the lifespan. Difficulties may involve locating appropriate resources to implement these newborn screening programs, but the funding provided would provide the necessary means to begin the process.

Summary

The Newborn Screening Saves Lives Reauthorization Act of 2021 (H.R. 482) would allow newborn babies to be screened for conditions that could lead to death and permanent disability if not found and treated early. Furthermore, the bill would reauthorize and make mandatory the Hunter Kelly Research Program at the NIH, and national surveillance activities conducted by the CDC. This would improve detection, prevention, and treatment strategies, as well as make consensus recommendations that would continue to guarantee the quality of laboratories involved in newborn screening. As healthcare professionals in a University Centers for Excellence in Developmental Disabilities (UCEDD), we see the impact that early screening can have on a person's life in our daily work. We strongly urge you to help eliminate preventable newborn deaths and severe disabilities by reauthorizing this bill.

Resources

S.350 - 117th Congress (2021-2022): Newborn Screening Saves Lives Reauthorization Act of 2021. (2021, February 22). https://www.congress.gov/bill/117th-congress/senate-bill/350

Sontag, M. K., Yusuf, C., Grosse, S. D., Edelman, S., Miller, J. I., McKasson, S., Kellar-Guenther, Y., Gaffney, M., Hinton, C. F., Cuthbert, C., Singh, S., Ojodu, J., & Shapira, S. K. (2020). Infants with congenital disorders identified through newborn screening — United States, 2015–2017. MMWR. Morbidity and Mortality Weekly Report, 69(36), 1265–1268. https://doi.org/10.15585/mmwr.mm6936a6