



**Statement for the Record Submitted by
Rahul Gupta, MD, MPH, MBA, FACP; Senior Vice President and Chief Medical and Health
Officer; March of Dimes
Hearing of the Health Subcommittee of the Committee on Energy and Commerce
“Reauthorizing Vital Health Programs for American Families”
Tuesday, June 25, 2019**

March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers representing every state, the District of Columbia and Puerto Rico, appreciates this opportunity to submit testimony for the record for the hearing, “Reauthorizing Vital Health Programs for American Families.” March of Dimes commends you for holding this hearing examining the vital role the federal government plays in supporting state newborn screening programs and the urgent need to renew those programs by passing the *Newborn Screening Saves Lives Reauthorization Act of 2019* (H.R. 2507).

Each day, thousands of newborns across the country will receive screening tests for medical conditions that, while not apparent at birth, have the potential to cause death or permanent disability if not treated early. For more than 12,000 families each year, newborn screening will be life-altering and, in many cases, life-saving.ⁱ Newborn screening allows babies with identified conditions to receive timely treatment allowing them to grow up healthy and thrive. Since newborn screening began in the United States almost 60 years ago, it has saved or improved the lives of hundreds of thousands of infants.

In the United States, newborn screening is a collaboration between federal and state governments. Each state runs its own newborn screening program by determining which conditions to include on its panel of tests, collecting specimens, performing screening tests, and developing follow-up systems to identify and treat infants who screen positive for a disorder on the panel. The federal government supports state programs by providing technical assistance, facilitating collaboration across states, and allocating financial resources to implement screening for new disorders and improve the quality of programs, among other activities. The federal government also convenes the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which is responsible for making recommendations to the Secretary of Health and Human Services (HHS) on opportunities to improve the nation’s newborn screening system. These recommendations include which conditions should be on the federal Recommended Uniform Screening Panel (RUSP), a list of disorders the HHS Secretary recommends for states to screen as part of their newborn screening panels.

Federal programs and investments are essential to nation’s newborn screening systems. The **Centers for Disease Control and Prevention (CDC)** is the world’s expert on newborn screening laboratory technology, providing quality assurance materials and technical assistance to

laboratories responsible for newborn screening in the United States and around the world. CDC also develops laboratory tests for new conditions eligible for newborn screening and provides financial support to state laboratories to implement screening tests for new conditions. The **Health Resources and Services Administration (HRSA)** improves the overall newborn screening system by facilitating collaboration and sharing of best practices across states; supporting the development of educational tools that states can use for patients, providers, and other stakeholders; assisting states to implement new conditions to state screening panels, and addressing emerging issues. The **National Institutes of Health (NIH)** advances the field of newborn screening by researching new screening technologies and new treatments. NIH also funds pilot studies to gather the necessary data to determine if a condition is an appropriate candidate for state newborn screening panels.

Activities administered by CDC, HRSA and NIH are both vital to improving that nation's newborn screening system and would not be undertaken by states without federal support. That is why it is essential that Congress reauthorize these programs before they expire at the end of the fiscal year by passing the *Newborn Screening Saves Lives Reauthorization Act of 2019*. March of Dimes strongly supports H.R. 2507 and its important provisions, including:

- Reauthorization of HRSA grants to help states expand and improve their screening programs, educate parents and health care providers, and improve follow-up care for infants with a condition detected through newborn screening.
- Reauthorization of CDC's Newborn Screening Quality Assurance Program, the only comprehensive program devoted to ensuring the accuracy of newborn screening tests.
- Reauthorization of the NIH's Hunter Kelly Newborn Screening program, which funds research aimed at identifying new treatments for conditions that can be detected through newborn screening and developing new screening technologies.
- Reauthorization of the ACHDNC, which provides states with the RUSP to help ensure every infant is screened for conditions which have a known treatment.
- Directing the National Academy of Medicine to develop policy recommendations to modernize the nation's newborn screening system.

Newborn screening is one of the greatest public health successes of the 20th century. Advancing medical and laboratory technologies, new therapies, and accelerated rare disease research promise continued success in the 21st Century, but only if state newborn screening programs can keep pace with the rapidly changing landscape. That is why it is essential to maintain and expand federal programs that will help states modernize their newborn screening programs and continue to save infants lives in the years to come.

March of Dimes again thanks you for holding this important hearing and stands ready to help you in advancing the *Newborn Screening Saves Lives Reauthorization Act of 2019* before the end of the fiscal year.

ⁱ CDC. CDC Grand Rounds: Newborn screening and improved Outcomes. Morbidity and mortality weekly report 2012;61(21);390-393.