



June 24, 2019

The Honorable Frank Pallone, Chairman
Committee on Energy & Commerce
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Greg Walden, Ranking Member
Committee on Energy & Commerce
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Pallone and Ranking Member Walden:

On behalf of the 25 to 30 million Americans with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to express support for the *Newborn Screening Saves Lives Reauthorization Act of 2019* (H.R. 2507).

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the over 270 organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Started in the 1960s, newborn screening has proven to be one of the most successful public health programs. Each year, approximately four million babies are screened using blood from a heel prick. Of that four million, screening identifies over 12 thousand infants with a disorder that, left undiagnosed and untreated, could cause severe developmental disability or death.

While administered at the state level, newborn screening programs depend heavily on the Federal Government for support. With support from the Federal Government, states have been able to expand the number of conditions they screen for and do so in a responsible manner, meaning that, among other things, the tests are appropriately calibrated for the population in order to avoid a high rate of false positives or negatives and there are follow-up programs in place to ensure necessary care. State programs have come a long way, but, with fewer than five states screening for all recommend conditions, there is still considerable work to be done.

The *Newborn Screening Saves Lives Act of 2008* authorized the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration to implement critical programs that have helped fund improvements in training and follow-up, operated vital research programs to advance newborn screening, established laboratory quality standards, increased public awareness and education, and grown the list of recommended conditions for states to screen (the Recommended Uniform Screening Panel or RUSP). This legislation was reauthorized in 2014 and, in order for these agencies to continue their lifesaving work, it must be reauthorized again by the end of September 2019.

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In addition to reauthorizing the agencies' work, H.R. 2507 would make focused improvements, such as increasing the funding available to states to expand and refine their programs. The legislation would also better facilitate the ability of the National Institutes of Health to accept private funding within the Hunter Kelly program, a research program established by the *Newborn Screening Saves Lives Act*, with the goal of amplifying the program's ability to carry out pilot studies involving multiple stakeholders. Enhancing the capacity of the Hunter Kelly program in this manner will help alleviate the growing need for pilot studies, particularly within disease communities that do not have the resources to carry them out on their own.

H.R. 2507 would help save the lives of thousands of babies who might otherwise be gravely harmed by an untreated rare disease. NORD appreciates your efforts to advance this legislation, and we look forward to working with you to ensure its successful passage.

Sincerely,

/s/

Rachel Sher
Vice President, Policy and Regulatory Affairs