

Physician Name  
Address  
Telephone  
Email Address

DATE

Dear Medical Provider:

We are writing to you to ask for your collaboration in reporting Newborn Screening (NBS) case definitions that are part of a quality improvement initiative of the Newborn Screening Technical assistance and Evaluation Program, or NewSTEPS. The program is designed to provide data, technical assistance and training to newborn screening programs across the country and to assist them with quality improvement initiatives. NewSTEPS is also a resource for medical providers who serve children with NBS conditions. Newborn screening programs nationwide screen for up to 31 Recommended Uniform Screening Panel (RUSP) core disorders, however each state has interpreted cases differently, resulting in an inability to compare prevalence or outcomes across states.

Standard surveillance case definitions of NBS conditions have been developed for harmonization across programs for national monitoring of children's health outcomes, thereby allowing for comparison of state to state data. NBS case definitions were developed by the Health and Human Services (HHS) Health Resources and Services Administration (HRSA) in cooperation with the medical sub-specialty community. The disease specialists on these panels used an iterative process to create definitions with diagnostic categories for each newborn screening disorder, along with a scale reflecting the certainty of the diagnosis. The experts have met in a combination of in-person meetings and conference calls and came to consensus on the definitions.

The definitions will be used by state newborn screening programs to categorize patients consistently across states. We are asking you to work with us to collaborate and provide data for the NBS case definitions. To facilitate the process, we kindly request pertinent information that will assist in this endeavor.

Thank you.

Newborn Screening Follow up Contact