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For Immediate Release

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Twenty states chosen to receive funding that will save babies' lives

Improvements in the timely reporting of newborn screening results can lead to early treatment

AURORA, Colo. (Feb. 9, 2016) – The ‘[NewSTEPS 360](#)’ program, a collaboration between the [Colorado School of Public Health \(ColoradoSPH\)](#) and the [Association of Public Health Laboratories \(APHL\)](#), has selected 20 states that will endeavor to improve newborn screening and save the lives of babies who are born with rare but serious conditions. These states are the initial cohort supported through a \$5.4 million dollar funding initiative from the Health Resources and Services Administration (HRSA).

Newborn screening (NBS) in the United States is routinely performed on more than 4 million newborns annually and saves or improves the lives of more than [12,000 infants](#). However delays in the timing of the diagnosis can lead to serious consequences or even death. NewSTEPS 360 aims to improve timeliness measures across the NBS spectrum. The program provides quality improvement training, individualized coaching of each state and the analysis of real time data impacting changes in selected state programs by shortening the timeframe between birth and identification. Following a rigorous application process 20 state/territorial NBS programs were chosen to participate in NewSTEPS 360:

- **Arizona** plans to improve the courier service for out-of-hospital births and utilize optical character recognition software to facilitate electronic demographic data entry.
- **Colorado and Wyoming** are partnering to create a video and toolkit along with a standardized curriculum for hospitals and midwives addressing timely collection and transport of newborn screening dried blood spot cards.
- **California** will launch intensive education for hospitals and midwives across the state and develop infographics for high performance hospitals. They will also investigate daily courier service processes to optimize delivery of specimens to state laboratories.
- **Hawaii** will provide training to providers to utilize a web-based data system to review newborn screening results and will partner with four large birthing facilities to enable electronic order entry and the reporting of newborn screening results using HL7 messaging (the accredited standards for the exchange, integration, sharing and retrieval of electronic health information).
- **Iowa** is developing an educational plan to ensure hospital-based and out-of-hospital birth NBS providers understand their role in assuring timely newborn screening, collection and shipment of dried blood spot cards.
- **Michigan** will utilize HL7 messaging with up to eight hospitals to develop demographic submission and results reporting to/from the state laboratory, and to verify receipt of the dried blood spot card by the laboratory.
- **Minnesota** is partnering with hospitals to facilitate data transfer from the hospital to the laboratory by capturing demographic information from the electronic health record and transferring the data to the dried blood spot card, and report results back to the electronic health record.
- **Montana** will improve the statewide courier service to enable hospitals and midwives to ship samples to the public health lab from all corners of the state.
- **Nebraska** will broaden their existing health information technology efforts by including more hospitals in their initiative to receive health demographic data entry, and perform results reporting via HL7 standard messaging
- **Delaware, Maryland, New Jersey, New York, and Virginia** are partnering together to offer educational

activities to health providers throughout their region to encourage the timely collection of newborn screening specimens and the efficient recall of infants with abnormal screens.

- **Oklahoma** is engaging in an education effort with birthing facilities to improve the collection of specimens and the understanding of the appropriate time to collect the specimens.
- **Puerto Rico** will provide education and feedback to hospitals and birthing centers on the importance of daily transport of dried blood spot cards to the laboratory, as well as developing an information tracking system to reduce the time of reporting results.
- **Tennessee** is continuing to improve the communication network and courier services to shorten the time to receive dried blood spot cards at the NBS laboratory and decrease the number of unsatisfactory specimens received.
- **Texas** will partner with birthing facilities and providers to promote rural demographic data entry through a web application. They will also develop training materials and videos for health care providers.
- **Virginia** will partner with hospitals to establish standards-based electronic order submission messaging, and in turn create tools and guidelines to facilitate the continued implementation in other hospitals and other states.
- **Wisconsin** will develop a system for the electronic submission of demographic information requested on the specimen card, and will establish an electronic HL7 data exchange of test orders and results between hospitals and the screening laboratory.

Over the next three years, NewSTEPS 360 will continue to provide financial and technical assistance to participating NBS programs, and will implement innovative processes to provide support to additional NBS programs in need of quality improvement services specific to timeliness in NBS.

This project is a collaboration with Newborn Screening Clearinghouse (Baby's First Test) housed at Genetic Alliance, the National Institute for Children's Health Quality (NICHQ), the Association of State and Territorial Health Officials (ASTHO), the Association of Maternal Child Health Programs (AMCHP), March of Dimes (MOD), the National Coordinating Center for Regional Genetics Collaboratives and the Newborn Screening Translational Research Network (NBSTRN), both housed at the American College of Medical Genetics (ACMG), and OZ Systems.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant UG8MC28554 - Improving Timeliness of Newborn Screening Diagnosis in the amount of \$5.4 million. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

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