BEACONS Selects Seven Sites, Finalizes Gene List for Genomic Newborn Screening Study

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Jim Sachetta January 28, 2026

One month old newborn baby

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3 min

Six states and one U.S. territory selected to assess feasibility of integrating

whole genome sequencing into public health newborn screening

Boston, MA Investigators leading BEACONS (Building Evidence and Collaboration for GenOmics in Nationwide Newborn Screening) today announced two major milestones in an NIH-funded research effort to evaluate genomic newborn screening: the selection of participating state and territorial newborn screening programs and the completion of a curated gene list focused on conditions actionable in the first year of life.

BEACONS has selected six states and one U.S. territory to participate in the study: Iowa, Minnesota, New York, Oregon, Puerto Rico, South Carolina, and Texas. These sites were chosen from over 20 states that volunteered through a rigorous evaluation process designed to reflect variation in geography, population served, and program readiness, all in support of BEACONS' goal of assessing feasibility across differing public health settings. BEACONS is launching with this initial cohort, with the potential to expand participation to additional states in the future.

BEACONS is the first award of the Newborn Screening by Whole Genome Sequencing (NBSxWGS) Collaboratory Initiative and is a multi-year research initiative designed to generate evidence on how whole genome sequencing can be responsibly, equitably, and sustainably incorporated into existing public health newborn screening systems across the United States. The study emphasizes close collaboration with state and territorial public health laboratories and programs, careful attention to ethical, legal, and social implications, and a strong commitment to public trust.

"Newborn screening has been one of the most effective and trusted public health programs for more than half a century," said Robert C. Green, MD, MPH, overall project lead for BEACONS. "By partnering with public health laboratories and programs across six states and one territory, BEACONS is building the evidence needed to understand how genomic sequencing can extend those benefits – bringing lifesaving information to families about their children while preserving the values that have made newborn screening successful."

Participating sites are currently engaged in planning and preparatory activities. BEACONS will recruit families through multiple pathways, including prenatal outreach, engagement at selected birthing facilities, and broader statewide outreach, ensuring that families across each participating jurisdiction have the opportunity to learn about the study and consider participation. Participation in BEACONS is entirely voluntary at no cost to parents, and will occur only with informed pareconsent. The genomic screening offered through BEACONS is designed to complement, and does not alter or replace, existing newborn screening services.

"Public health laboratories and programs are central to evaluating genomic newborn screening in real-world systems," said Jelili Ojodu, MPH, BEACONS co-investigator and senior director of Newborn Screening and Genetics at the Association of Public Health Laboratories (APHL). "BEACONS enables states and territories to help define what feasibility looks like in real-world practice, while maintaining universal access, quality, and public confidence in newborn screening."

In parallel, BEACONS investigators have finalized a curated list of 746 genes associated with 777 conditions for which early identification in infancy could enable timely intervention to improve health outcomes in the first year of life. The gene list was developed through a rigorous, multi-step process informed by national and international consensus recommendations and broad stakeholder input, including clinicians, geneticists, laboratorians, public health partners, rare disease advocates, parents, and NIH leadership. The gene list will continue to evolve as new evidence and therapies emerge and will be made publicly available at www.beaconsnbs.org.

“Selecting which conditions to include in genomic newborn screening is both a scientific and ethical responsibility,” said Nina Gold, MD, MS, multiple principal investigator and lead for gene list development. “Our focus has been on conditions where early action can meaningfully change a child’s health. Transparency around this process is essential as the field continues to advance.”

BEACONS is led by investigators from Mass General Brigham, Ariadne Labs and Harvard Medical School, Boston Children’s Hospital, Albert Einstein College of Medicine, Children’s Hospital at Montefiore, Case Western University, Baylor College of Medicine, and the Association of Public Health Laboratories (APHL), in collaboration with GeneDx, Illumina, and additional academic, public health, and community partners.

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For more information about BEACONS, here is a fact sheet from BEACONS launch in October, 2025, visit www.beaconsnbs.org or contact info@beaconsnbs.org.

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