

NIH Makes \$14.4 Million Award to Launch Initiative to Bring WGS to Newborn Screening

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Rare Daily Staff

The National Institutes of Health awarded \$14.4 million to launch BEACONS, the first and largest multistate genomic newborn screening initiative in the United States.

BEACONS, short for Building Evidence and Collaboration for GenOmics in Nationwide Newborn Screening, will assess the feasibility of integrating whole genome sequencing into the U.S. newborn screening program. The goal is to make the technology easier and more affordable for

states to access, while addressing parents' and caregivers' concerns about privacy and consent, and focusing only on genes and variants treatable in the first year of life.

The initiative will enroll up to 30,000 newborns in as many as 10 states over the next three years.

The three-year program is a cooperative effort among the NIH Common Fund, the National Center for Advancing Translational Sciences, and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

Multiple principal investigators are leading the initiative. They include Robert Green and Nina Gold of Mass General Brigham and Harvard Medical School; Ingrid Holm of Boston Children's Hospital and Harvard Medical School; and Melissa Wasserstein of Children's Hospital at Montefiore and Albert Einstein College of Medicine.

The team also includes leadership from the Association of Public Health Laboratories, as well as additional investigators from medical centers around the nation.

The NIH budget will be supplemented by contributions from sequencing partners GeneDx and Illumina, and the effort will bring together experts, public health labs, and community partners to study how whole genome sequencing could be integrated into newborn screening nationwide.

"By bringing the power of genomics to the very start of life, we have the potential to shorten, and one day eliminate, the diagnostic odyssey that so many families endure," said Britt Johnson, senior vice president of medical affairs at GeneDx. "This collaboration marks an exciting and transformative step toward a future where every child has the opportunity to live a healthier, fuller life."