BEACONS Fact Sheet and Quotes – October, 2025

Overview

BEACONS (Building Evidence and Collaboration for GenOmics in Nationwide Newborn Screening) is the nation's first coordinated, multi-state genomic newborn screening initiative.

It is led by investigators from Mass General Brigham and Ariadne Labs, Boston Children's Hospital, Albert Einstein College of Medicine, the Association of Public Health Laboratories (APHL), Case Western Reserve University, Baylor College of Medicine, GeneDx and Illumina.

BEACONS will pilot the integration of whole genome sequencing into existing state newborn screening systems using the blood spot that is currently collected at birth by state public health laboratories. The study will recruit, consent, and enroll up to 30,000 newborns in as many as 10 states over the next three years as the beginning of a broader national initiative, with the potential to scale beyond the initial recruitment to millions of newborns.

BEACONS is funded by a $27 million award ($14.4M from the National Institutes of Health (NIH) Common Fund Venture Program and $12.6M from GeneDx and Illumina).

BEACONS will

- Enroll up to 30,000 newborns across as many as 10 states over three years with the potential to expand into additional states and millions of newborns
- Evaluate feasibility of embedding whole genome sequencing into public health newborn screening workflows using the blood spot that is currently gathered on all newborns immediately after birth
- Include early identifiable, treatable conditions, starting with conditions actionable in the first year of life
- Be guided by a Community Advisory Board composed of parents, advocates, leaders, clinicians, genetic counselors, bioethicists, and privacy experts
- Include strong parental education and consent and privacy protections
- NIH Funding: NIH Common Fund Venture Program ($14.4M), Award No. 1OT2OD040029-01
- Industry Funding: $12.6M of in-kind support from GeneDx and Illumina

Contributors & Roles

- Contact and co-lead investigator: Robert Green, MD, MPH (Mass General Brigham, Ariadne Labs, Broad Institute, Harvard Medical School)
- Co-lead investigators: Ingrid Holm, MD, MPH (Boston Children's Hospital, Harvard Medical School); Nina Gold, MD, MS (Mass General Brigham, Harvard Medical School).
- Co-lead investigator: Melissa Wasserstein, MD (Albert Einstein College of Medicine / Children's Hospital at Montefiore Einstein).
- Ethical, legal, social implications (ELSI) leadership: Aaron Goldenberg, PhD, MPH (Case Western Reserve University School of Medicine) and Stacey Pereira, PhD (Baylor College of Medicine).
- Public health alignment: APHL's Newborn Screening & Genetics program directors Jelili Ojodu, MPH and Sikha Singh, MHS, PMP (co-investigators).
- Industry representatives: Britt Johnson, PhD (GeneDx), Swaroop Aradhya, PhD (Illumina)

Additional Context

- The first sequencing of healthy newborns began with the BabySeq Project in 2015. For more see Robert Green's 2025 TED talk. Since then, over 30 pilot programs worldwide have been launched.
- Drs. Green, Dr. David Bick and Mr. Nic Encina founded the International Consortium on Newborn Sequencing in 2022 as a forum for sharing experiences of programs around the world. BEACONS represents the first coordinated national initiative in the US, and may serve as a counterpart to the UK's GENERATION Study.

Quotes from Investigators

"For more than 50 years, newborn screening has been a beacon of trust, saving children's lives by analyzing a few drops of blood after birth. BEACONS brings the next generation of hope, giving families the option of genomic screening for hundreds of additional conditions that can be treated from birth, in an era when gene and cell therapies are rapidly expanding treatment possibilities. Together, families who volunteer in participating state programs will be collaborating in a national effort to give every child the brightest start to life." — Robert Green, MD, MPH (Mass General Brigham, Ariadne Labs, Broad Institute, Harvard Medical School)

"Knowledge is power. Identifying early that a child has a treatable or preventable condition gives the child the best chance for a healthy life. It also means parents won't have to go through the long diagnostic odyssey that is so common in children with rare diseases, sometimes delaying a diagnosis until it is too late to provide treatment." — Ingrid Holm, MD, MPH (Boston Children's Hospital, Harvard Medical School)

"Selecting which genetic conditions to include in screening is a complex process that will involve the input of rare disease advocates, state public health laboratories, and evidence from prior research studies. We will develop a list of conditions which, when identified early, can meaningfully improve the health of a child." — Nina Gold, MD, MS (Mass General Brigham, Harvard Medical School)

"We will rely on the input of parents and community leaders to make sure that newborn screening expansion is done in a thoughtful and transparent way. This is about building trust as much as building science." — Melissa Wasserstein, MD (Albert Einstein College of Medicine / Children's Hospital at Montefiore Einstein)

"Evaluating the feasibility of genomic newborn screening requires careful attention to ethical, legal, and social concerns. Our study will explore ways programs can reflect parental and public values, protect a newborn's privacy, preserve universal access, and enhance the benefits of newborn screening for all families." — Aaron Goldenberg, PhD, MPH (Case Western Reserve University School of Medicine)

"APHL is proud to join this partnership in bringing whole genome sequencing to newborn screening in a way that will provide more information to families and save even more babies' lives. We welcome the opportunity to bring innovation to the public health laboratory community and the newborn screening system." — Jelili Ojodu, MPH (Association of Public Health Laboratories)

"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. This collaboration marks an exciting and transformative step toward a future where every child has the opportunity to live a healthier, fuller life." — Britt Johnson, PhD (GeneDx)

"Integrating genomics into healthcare starting at birth to reduce the burden of genetic diseases has been an important concept since the Human Genome Project. Research conducted by this group will produce critical insights that inform proper use of whole genome sequencing for newborn screening in the US public healthcare setting." — Swaroop Aradhya, PhD (Illumina)

Contacts and Resources

More about BEACONS, visit www.beaconsnbs.org or write to info@beaconsnbs.org

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