

CCHF Issues Parent Advisory on NIH-Funded Newborn Genome Sequencing Project

NIH-funded BEACONS embeds whole genome sequencing into state newborn screening systems

ST PAUL, MN, UNITED STATES, May 18, 2026 /EINPresswire.com/ -- Citizens' Council for Health Freedom (CCHF) is warning parents that the \$14.4 million NIH-funded BEACONS project will use newborn blood spots collected at birth to fully sequence newborn genomes through state newborn screening systems.



Building Evidence and Collaboration for GenOmics in Nationwide Newborn Screening (BEACONS), launched October 1, 2025. Operating in up to 10 states over three years, the project will seek to enroll at least 30,000 newborns.

Recruitment began in April. The first phase includes Iowa, Minnesota, New York, Oregon, Puerto Rico, South Carolina and Texas. BEACONS has finalized a list of 746 genes associated with 777 conditions considered actionable in the first year of life.

"Two decades ago, CCHF learned that state health departments were storing, using and sharing newborn DNA and the test results of newborn genetic screening without parental consent. Our efforts have stopped some of the storage, but many states continue to retain the DNA of these newborn citizens." said Twila Brase, RN, PHN, president and co-founder of CCHF. "BEACONS expands the government's genetic intrusion. Though parent consent is required, this project would sequence a baby's entire genome before the child ever has a chance to say no."

CCHF created [ItsMyDNA.org](https://www.ItsMyDNA.org) to warn parents that newborn dried blood spots collected after birth from the baby's heel contain the child's DNA and that some states make these blood spots available for research without parental consent. CCHF also orchestrated the first parent lawsuit in the nation against state government storage, use and dissemination of "Baby DNA" without parental consent, *Bearder et al. v. State of Minnesota*, Court File No. 27-CV-09-5615. The case

resulted in a 2011 Minnesota Supreme Court ruling requiring written informed consent before the Minnesota Department of Health could store, use or disseminate newborn blood spots after newborn screening was complete. The plaintiffs were represented by Farrish Johnson Law Office, Chtd., 1907 Excel Drive, Mankato, MN 56001; (507) 625-2525; farrish@farrishlaw.com.

BEACONS will use the newborn blood spots already collected by state public health laboratories for newborn screening. To sequence the child's whole genome, BEACONS will take eight additional 3.2 mm punches from the multiple blood spots collected on the filter paper card used for newborn screening.

CCHF warns that parents could be approached shortly before or after birth—a vulnerable time—and asked to authorize whole genome sequencing (WGS) without fully understanding the possible lifelong consequences for their child.

"Parents need to know where the results will be recorded, who will have access, how long the data will exist and whether this information could be used against the child later," Brase said. "Will they be told the negative consequences of false positives, which will only increase because of the enormous increase in conditions tested for?"

A 2010 UCLA study published in the Journal of Health and Social Behavior on expanded newborn screening described the families involved as the "collateral damage of newborn screening" after abnormal results left parents uncertain for years whether their children were false positives or true positives.

"Government must not be in the business of sequencing the genomes of citizens, and the public should not condone it—or pay for it," Brase said. "Whole genome sequencing should never be done without the consent of the subject. A newborn cannot consent."

Media inquiries and interview requests for Twila Brase should be directed to Alexandra de Scheel at media@cchfreedom.org.

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About Citizens' Council for Health Freedom:

Since 1998, CCHF has existed to protect patient and doctor freedom. As a national, independent, non-partisan, non-profit health freedom organization, CCHF maintains a patient-centered, privacy-focused, free-market perspective. For more information, visit: www.cchfreedom.org.

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