Newborn Screening Data Snapshot – 2024

January 2026

2024 in Review

Indiana's Public Health Genetics program continuously strives for quality and program improvement in NBS education, processes, data collection and reporting in order to identify, support, and improve the lives of those identified with a NBS condition. NBS quality indicators (QIs) are metrics used to track and assess statewide NBS processes, measured within the submitting birthing facilities and the NBS laboratory to identify areas of improvement, ensuring all Hoosier families receive the best possible care throughout the NBS process. Early Hearing Detection and Intervention's (EHDI) goals are mandated by state and federal law to include a 1-3-6 screening model to ensure all infants receive their hearing screen, diagnostic assessment if needed, and be enrolled in early intervention if needed. This data snapshot outlines Indiana's dried blood spot (DBS) QIs for specimens collected in 2024 and EHDI's 1-3-6 for the 2024 birth year.

36 out of 38
DBS conditions on the recommended uniform screening panel (RUSP) are on Indiana's NBS panel

79,788 Initial DBS received
11,293 Repeat DBS received

Most Prevalent Confirmed NBS Disorders in 2024

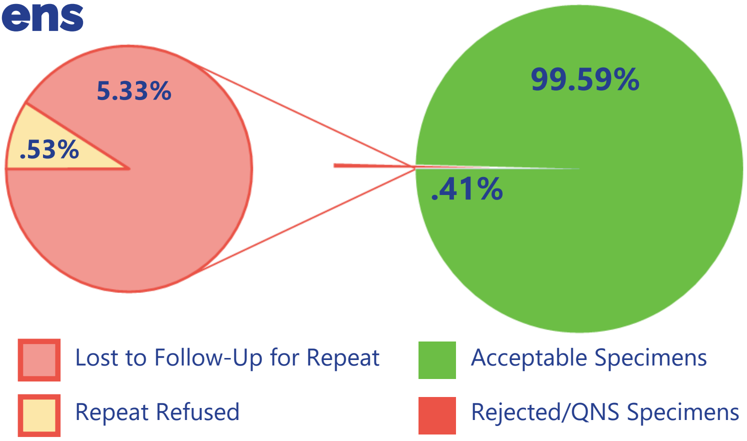
- Congenital Hypothyroidism: 58
- Sickle Cell Anemia: 24
- Cystic Fibrosis: 18
- Spinal Muscular Atrophy: 8
- Congenital Adrenal Hyperplasia: 5
- Classic Phenylketonuria: 5

QI 1 - Unsatisfactory Specimens

QI 4a - Lost to Follow-Up

QI 1 is the percent of DBS specimens that were unacceptable and rejected due to improper collection and quality.

QI 4 is the percent of infants that have no recorded final resolution with the NBS Program, meaning they are lost to follow-up (LTF). QI 4a is specific to unacceptable and rejected specimens, connecting back to QI 1.



QI 2 - Missing Essential Information on NBS Card

QI 2 is the percent of DBS specimens with at least one missing state defined essential data field (information critical for testing and follow-up) on a NBS card upon receipt at the NBS laboratory.

There are some Indiana birthing hospitals with significant challenges with completing all essential information, so this remains a 2026 focus for Public Health Genetics.

Indiana 3.86% (3,469 specimens)
National Median 3.16% (28 NBS programs)

QI 5a - Timeliness

98.2% **of DBS specimens are collected within 48 hours of birth in 2024**

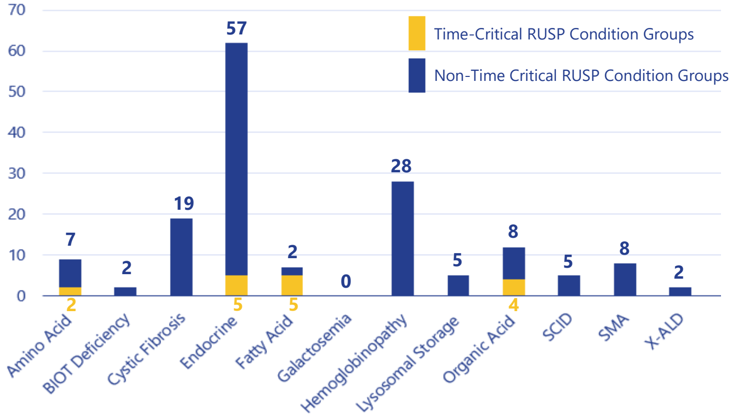
Indiana is performing above the national average in terms of collecting specimens within 48 hours of birth.

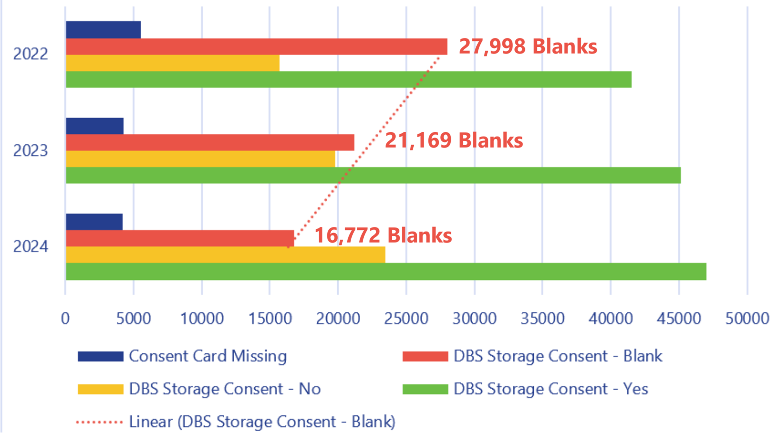
As of 12/1/25, the national average across 36 NBS programs for 2024 is **97.7%** while the standing national goal is **95.0%.**

QI 7 Confirmed Positives: 2024 Births

For infants born in 2024, there were 159 confirmed reportable RUSP conditions, with 16 being time-critical (yellow) and 143 being non-time critical (blue).

There were 272 confirmed carriers of various RUSP conditions that are not reported to NewSTEPs.





DBS Storage Consent

By law, IDOH requires hospitals, birthing centers, midwives, and attending physicians to ensure that every DBS consent card is fully completed, including a checked "**YES**" or "**NO**" box and a parent or guardian's signature.

Consent cards cannot be left blank.

PHG hopes to see a continuing downward trend of blank consent cards in 2026.

EHDI's 2024 1-3-6 Definition

1 All infants born in Indiana should receive a newborn hearing screen prior to **1** month of age.

3 All infants who do not pass their newborn hearing screen should receive an audiology diagnostic assessment before **3** months of age.

6 All infants identified with permanent hearing loss should be enrolled in early intervention before **6** months of age.

1 **98%** of Indiana infants received newborn hearing screenings by 1 month of age, **matching the national average of 98%.**

3 **48%** of Indiana infants diagnosed as deaf or hard of hearing were diagnosed by 3 months of age, **surpassing the national average of 38%.**

6 **52%** of Indiana infants diagnosed as deaf or hard of hearing were enrolled in early intervention by 6 months of age, **surpassing the national average of 40%.**

Looking Ahead to 2026

Based on the above metrics, the Public Health Genetics program is continuing to evaluate and improve the family and birthing facility education around NBS processes to decrease the QNS rates, hopefully retroactively decreasing the lost to follow-up rates on unacceptable specimens.

Targeted birthing hospital education and trainings with facilities having high rates of missing essential information on the NBS card and blank DBS consent cards will be an area of focus for Public Health Genetics to ensure all aspects of the NBS card and DBS consent card are understood and completed by necessary parties to improve QI 2 and DBS consent rates.

Indiana EHDI's 2026 goals include activities and collaboration with healthcare providers, birthing hospitals and parents to improve the number of deaf and hard of hearing children being identified by 3 months of age and enrolled in early intervention by 6 months of age.

For additional information on DBS QI data and EHDI's 1-3-6 data, email NewbornScreening@health.in.gov

Indiana Department of Health