

Genomics & Newborn Screening (GNBS) News



Hello, Newborn Care Team,

Thank you for participating in the Birthing Facility Outreach. As we met with each of you, a common request was better and more direct communication from the ISDH GNBS team. We are offering this newsletter as a way to communicate with all of Indiana's birthing facilities and stakeholders. We envision these newsletters as a way to best serve all stakeholders involved in the care of newborns, a connection to resources and updates that will benefit everyone, especially our newborns, to help reduce Indiana's infant mortality rate.

Did you know?

About 23% of Indiana's infant mortality rate is attributed to chromosomal anomalies and congenital malformations.

What is INSTEP?

Indiana Newborn Screening Tracking & Education Program (INSTEP), is a centralized, web-based location for data entry and management. Those involved with mandatory NBS monthly reporting (MSRs) are familiar with the program. INSTEP improves access to NBS results for birthing facilities, health care providers, and GNBS Program personnel. Data from INSTEP is also used to enhance standards of care for children diagnosed with NBS conditions.

Need access to INSTEP? Please email ISDHNBS@isdh.IN.gov

In the Spotlight

*Congratulations to **Adams Memorial Hospital** for ranking as one of the most efficient and effective GNBS systems among all of the birthing facilities in Indiana. Nice work!*



ISDH GNBS Team

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*Please email the GNBS
team for further help or
information.*

*Check out the back
page for more
important updates.*



**Indiana State
Department of Health**

IMPORTANT UPDATES

NEW Panel Conditions

This year, Indiana has added two new conditions to the GNBS panel. The panel includes the 47 genetic conditions previously screened plus two new conditions. Indiana will begin screening for 49 conditions beginning July 1. The two new conditions screened for are severe combined immunodeficiency (SCID) and spinal muscular atrophy (SMA). Both are screened through the heelstick. Indiana will be one of the first states to begin screening for SMA as it was recently added to the Recommend Universal Screening Panel (RUSP).

SCID is also known as the “Bubble Boy Disease” and occurs when a baby’s immune system does not work. Babies with SCID are not able to fight infections. They appear healthy at birth but can become sick very quickly when exposed to common illnesses.

SMA is a disorder that affects the nervous system. SMA damages the nerve cells that control muscles. Because of this, a child with SMA cannot move or breathe normally and will get weaker over time. There are four different types of SMA that vary in severity.

NEW 24-hour rule

Indiana has also implemented a change for the timing of the heelstick. Each newborn **must be screened 24 hours after birth**. The original rule was 24 hours after first protein feed and 48 hours after birth. Advances in the card technology supports earlier testing for a quicker turnaround of the results.

Heelstick Special Cases (<2,000 grams/NICU)

Best practice to obtain the heelstick:

1. 24 hours after birth
2. Sixth day after birth*
3. Fourteenth day after birth*
4. Thirty days after birth*

**or day of discharge, whichever comes first*



What is the IBDPR?

The Indiana Birth Defects and Problems Registry (IBDPR) is a population-based surveillance system that seeks to promote fetal, infant and child health. It is every physician's responsibility to report to the Indiana Birth Defects and Problems Registry (IBDPR) using the Physicians Reporting Tool. Conditions reported to IBDPR are both reportable and targeted. Reportable conditions are **mandated by law**. This data allows us to detect trends, address community concerns, and make programmatic decisions to offer education and awareness of conditions. Since birth defects are the second leading cause of infant mortality in Indiana, these decisions are aimed at reducing infant mortality.

Need access to Gateway or the Physicians Reporting Tool? Please email IBDPR@isdh.IN.gov.

