

Genomics & Newborn Screening (GNBS) News



Hello, Newborn Care Team,

Thank you to our birthing facilities for participating in the *Birthing Facility Outreach!* We have already seen significant increases in timeliness, quality and communication regarding GNBS! As the team continues to meet through 2018, we encourage you to remain up-to-date with your facility's *Maintaining a Centralized Program (MCP)* form. The MCP form helps keep our stakeholder contact information current, and it benefits each of you at the facilities by enabling you to reach your fellow stakeholders in each department to improve internal communications and efforts.

In the Spotlight

*Congratulations to **St. Vincent Carmel** on being one of the most efficient and effective GNBS systems among all of the birthing facilities in Indiana. Great work!*

New Newborn Screening Conditions

Please share the following information with families and other stakeholders! Severe Combined Immunodeficiency (SCID) and Spinal Muscular Atrophy (SMA) have been added to Indiana's NBS panel this year. In order to implement and fund these additions, the NBS fee increased to \$100 beginning July 1. This fee is paid by the families through insurance or self-pay.

SCID, also known as the "Bubble Boy Disease," is a disorder in which abnormalities exist in a baby's immune system. Babies with SCID are not able to fight infection and they appear healthy at birth but typically fail to gain weight and can become sick quickly when exposed to common illnesses.

SMA is a disorder that affects the nervous system by damaging the nerve cells that control muscle movement. There are four primary types of SMA, each with varying degrees of severity. Depending on the type, SMA weakens the muscles of the body making it unable to walk, eat or breathe. SMA is one of the leading genetic causes of Indiana's elevated infant mortality rate.



Contact Us!

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EHDI Team

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Please email the GNBS team for further help or to ask questions!

You can find the Birthing Facility Outreach Toolkit online at

www.NBS.IN.gov

for more information.



Indiana State
Department of Health

What is EHDI?

The Early Hearing Detection and Intervention (EHDI) program aims to screen by 1 month, have confirmatory evaluation by 3 months to identify hearing loss, and act on early intervention by 6 months.



Mandated by Indiana Statute IC 16-41-72-2, the Universal Newborn Hearing Screening (UNHS) can be performed as early as six hours after birth, but it is recommended to wait until 12 hours to allow fluids to clear out of the ears. Similar to the heelstick and pulse oximetry screens, the UNHS needs to be completed prior to discharge.

When an infant has not passed two newborn hearing screens prior to discharge, it is best practice that not more than two inpatient hearing screens are done. Therefore, birthing facilities are responsible for providing a referral to a diagnostic audiologist, and/or to the primary care physician for follow-up. The birthing facility is also required to report the hearing screening results to the EHDI program.

Please see the *EHDI Program Manual* within the *Birthing Facility Outreach Toolkit* available online at www.NBS.IN.gov or more information.

Did you know?

In 2016, 37 Hoosier babies died due to congenital heart defects (CCHD). The pulse oximetry portion of NBS is a simple and effective way to detect, intervene and prevent infant mortality

Have a Courier question?

NOW Courier service is used statewide for all newborn screening specimens and ensures timely delivery to the NBS Lab in Indianapolis. *NOW* serves most all birthing facilities six days a week. Contact *NOW Courier* or the NBS Laboratory with any questions. If your facility does not have a high birth volume that requires a set schedule, you are able to indicate the need for pick up Monday through Friday by emailing:

NewbornScreening@NowCourier.com

