



Indiana
Department
of
Health



Genomics and Newborn Screening Newsletter

March 2023



A Day of Observance

Join the Indiana Birth Defects and Problems Registry team in observing World Birth Defects Day on March 3. World Birth Defects Day was established in 2015 to help spread awareness and unite in birth defects prevention, proper treatment, and overall care. Raising awareness and increasing accessibility and inclusion can help with breaking down the barriers that the birth defects community faces. There are thousands of different birth defects but the most common are heart defects and neural tube defects. In Indiana, birth defects are the second leading cause of infant mortality. Also, about 2,500 babies are born with a birth defect each year in Indiana. For additional information and to find out how you can get involved please visit the link below. #WorldBDday #ManyBirthDefects1Voice #WorldBirthDefectsDay

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Newborn Screening

2023 Facility Site Visits

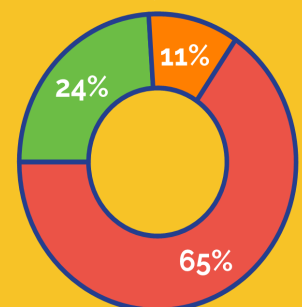
The NBS program under GNBS will resume regular site visits to all birthing hospitals and licensed birth centers across the state of Indiana during 2023! The visits provide a platform for partners in the field to request facility-specific assistance and advice in an effort to improve the overall newborn screening system. Main topics to be discussed include heel stick quality, CCHD screening protocol, newborn screening documentation and reporting, NBS card transit and dried blood spot storage consent. We thoroughly enjoy the opportunity to meet all of our essential partners within the NBS system!

Small Spots, Big Impact

The quality of all newborn blood spots is monitored by NBS Lab staff each day! This effort helps to quickly identify poor quality that can lead to delay in timely detection of and intervention in serious conditions. A review of all 2022 blood spot quality indicators revealed that 65% were due to poor heel stick collection practices; with a total of 445 samples being entirely rejected due to poor heel stick collection. GNBS has resources available to help promote heel stick collection best practices.

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2022 Quality Indicators



- Delays in Transit to NBS Lab
- NBS Card Incomplete or Expired
- Poor Heel Stick Collection

Rare Disease Day

Feb. 28 is Rare Disease Day. This is a globally observed day to bring light to the continual efforts being made around the world for rare disease treatment and care. There are about 300 million people internationally who have been diagnosed and are living with a rare disease today. About 72% of them have genetic conditions. Diagnosing, treating, and living with a rare disease, life threatening or not, brings many challenges for patients and families. Many rare diseases have varying symptoms, presenting at first as something common. It can sometimes take many years and many specialists to confirm diagnosis and start proper therapy. Many disorders still do not have specific or effective treatments, even once diagnosed. Rare Disease Day brings awareness that together we can advocate for equitable health care.

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Meet Lanessa Austin!

Lanessa is one of the newest members of the GNBS team, serving as the newborn screening follow-up specialist. She brings years of experience of work reducing infant mortality and prenatal and child development education. Lanessa is a Certified Community Health Worker, a trained Safe Sleep Ambassador, and an endorsed infant mental health family specialist. She sits on the Indianapolis Health Babies Fetal Infant Mortality Review Team, the Marion County Safe Sleep Work Group, and Healthy Families Advisory Committee. Lanessa received her BS in liberal studies/psychology from the University of Indianapolis. In her free time, she and her husband are enjoying their recent empty nest status, as both of their daughters pursue higher education and careers out of state.



Did You Know?

Congenital Heart Defects

Congenital heart defects affect the structure of the heart and how the blood flows through the body. In the United States, about 40,000 births are affected by a congenital heart defect annually. Congenital heart defects are the most common types of birth defects in the United States and Indiana. About 1,000 babies are born with a congenital heart defect in Indiana each year. In 2012, Indiana began screening every infant using [pulse oximetry to detect critical congenital heart defects](#), which often require surgery shortly after birth. Over the years, medical treatment has improved and most babies diagnosed with a congenital heart defect live long and healthy lives! For additional resources please visit the link below.

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To **promote**, **protect**, and **improve** the health and safety of all Hoosiers

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