

Genomics & Newborn Screening (GNBS) News



Hello Newborn Care Team,

There was recently a new rule promulgation period in 2018 where the rule pertaining to newborn screening was updated. Please print and distribute this to all appropriate partners. The most up-to-date rule can be found at www.in.gov/legislative/iac/iac_title?iact=410.

Perinatal Genetics and Genomics Advisory Committee

At the end of 2018, the Indiana Perinatal Quality Improvement Collaborative (IPQIC) established a task force for Perinatal Genetics and Genomics. The first task force meeting took place in December 2018 with participants from many groups, including geneticists, OB/GYNs, neonatologists, pediatricians, genetic counselors, disease specialists, laboratory specialists, Family and Social Services Administration, advocacy representatives, as well as local representatives from American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American College of Medical Genetics and Genomics, and others.

This task force is charged with ongoing advisement of programmatic practices of the ISDH as they relate to genomic healthcare for perinatal health improvement efforts and fatality prevention. This includes both detection and intervention of pre-pregnancy genetic carrier screening, prenatal genetic testing, newborn genetic screening, birth defects monitoring and genetic fatality review. With each genetic screen, an action plan for intervention and connection to appropriate healthcare is needed.

Please email perinatalcollab@att.net for more information.

Contact Us!

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

For more information or resources please visit our website at www.NBS.IN.gov



**Indiana State
Department of Health**

National Birth Defects Prevention Month

During January, National Birth Defects Prevention Month - 2019, the Indiana Birth Defects and Problems Registry (IBDPR) at the Indiana State Department of Health (ISDH) joined with the National Birth Defects Prevention Network (NBDPN) and the Centers for Disease Control and Prevention (CDC) to increase awareness of birth defects and how they can be prevented.

The IBDPR is actively working to raise awareness of how prevalent birth defects are and what steps can help to prevent them. In the United States, a baby is born with a birth defect every 4½ minutes – about 120,000 babies each year. Birth defects are the second leading cause of death in Indiana. In 2016, 138 Hoosier infants died due to congenital malformations, which accounted for 22 percent of infant deaths.

The National Birth Defects Prevention Month campaign theme, “**Best for You. Best for Baby,**” aims to raise awareness of the roughly 2,500 birth defects cases occurring in Indiana each year. Click [here](#) for the 2019 prevention month toolkit.

Please encourage all pregnant women and those who may become pregnant to:

- Be sure to take 400 micrograms (mcg) of folic acid every day.
- Book a visit with your healthcare provider before stopping or starting any medicine.
- Become up-to-date with all vaccines, including the flu shot.
- Before you get pregnant, try to reach a healthy weight.
- Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco and other drugs.

In the Spotlight!

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



Have you used the new Religious Refusal waiver?

Per law (IC 16-41-17-2), a family is able to refuse one, two, or all three portions of the newborn screening due to religious beliefs. Always report religious refusals by submitting the completed signed waiver to ISDH by emailing the forms directly to the GNBS Program at ISDHNBS@isdh.IN.gov. We have updated the Religious Refusal waiver as of early 2018. We see many facilities submitting old waivers that do not meet requirements. Please find the new Religious Refusal waiver [here](#) on our website at www.NBS.in.gov under *Resources-State Forms* section.

