Indiana Department of Health

Genomics and Newborn Screening Newsletter

Fourth Quarter 2023

News & Events

Community Events and Printed Material Requests

The Genomics and Newborn Screening (GNBS) Program exhibited at 26 conferences and community events around the state in 2023! We value community engagement and are eager to continue to participate in community-based events throughout 2024.

Please share information and invitations for upcoming events or exhibiting opportunities for the GNBS team to NewbornScreening@health.in.gov.

GNBS is happy to announce that our educational handouts for families are now available in six new languages. In addition to English and Spanish, handouts are now available in Arabic, Burmese, Chinese, French, German, and Haitian Creole. These handouts can be found under the Resources for Families tab on our website.

Printed materials can be requested in English or Spanish by completing the GNBS Material Request Form. Requests for printed materials in any of the six additional languages will be available in 2024, stay tuned!

2023 Highlights

Newborn Screening

In November, the Newborn Screening (NBS) program completed its final in-person visits to all Indiana birthing hospitals and facilities. Thank you to all the sites for welcoming our team and continuously working to ensure all Hoosier newborns have timely and good quality newborn screening!

We would also like to extend a special thank you to all MSR reporters for your diligence in ensuring cases are reported so timely follow-up can occur.

Indiana Birth Defects and Problems Registry

The Indiana Birth Defects and Problems Registry (IBDPR) would like to give a special thank you to all birth defect registry reporters for your timely submissions this year. We appreciate your hard work and dedication!

January is National Birth Defects Awareness month! Please be sure to check our website and social media for prevention information and resources. Additional information may also be found on the National Birth Defects Prevention Network (NBDPN) website.

Metabolic Formula Program

The Metabolic Formula Program kicked off July 1, 2023 and has already had a positive impact on metabolic patients and families across Indiana. We have provided formula for a total of 32 patients whose range of diagnoses include PKU, Propionic Acidemia, and other varying inborn errors of metabolism. These patients come from both metabolic clinics: IU Health Medical and Molecular Genetics at Riley Children's Hospital and the Community Health Clinic in Shipshewana, IN. We are so happy to have this program and continue to get positive feedback from those it is supporting.

Meet Abby Hall!

Abby has been with GNBS for a year. She came to us with 10 years of experience from Riley Hospital for Children where she was one of the dietitians who treated kids and adults with rare metabolic disorders. She has brought her expertise and most importantly her passion to our team to help further expand and improve the Indiana Metabolic Formula Program. This program helps provide financial support to patients and families in Indiana with poor or no insurance coverage for their medically necessary nutritional supplements. For many metabolic disorders, diet is the cornerstone of their treatment and without it they would suffer from intellectual and developmental disabilities along with severe nutritional deficiencies. This program aims to help fill in the gaps and be an added support to all patients in Indiana, including the Amish communities. Abby studied nutrition and dietetics at Indiana University and did her graduate study and internship at Buffalo University – SUNY. She is eager to see how she can help expand the Metabolic Formula Program and continue to support metabolic patients and medical teams in Indiana.

Onward to 2024

Perinatal Genetics & Genomics (PGG) Committee

The Perinatal Genetics and Genomics Committee was established in 2018 to advise the GNBS program. The committee created a nomination and evaluation process for adding conditions to newborn screening in 2021. As a result of HEA 1254 from the 2022 legislative session, a requirement of this committee is to "recommend the addition of a disorder to, or deletion of a disorder from, the required examination under this subsection." This work is critical to the success Indiana's newborn screening program. The committee discusses other issues around genetics and genomics as well.

We welcome additional experts in genetics and genomics to join the committee, and we're excited to continue the critical work of the committee in 2024!

If you are interested in joining the PGG, please email GNBS Program Director Allison Forkner at AForkner@health.in.gov.

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

Indiana Department of Health

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