



Indiana  
Department  
of  
Health

# Genomics and Newborn Screening

Spring 2024 Newsletter

## Spotlight



### April is Autism Acceptance Month

April is Autism Acceptance Month. Join the Genomics and Newborn Screening team as we raise awareness to promote autism acceptance, celebrate neurodiversity and individual differences, and continue to advance inclusivity and connectedness throughout the community. The color blue, associated with calmness and acceptance, is the primary color designated for autism. Its popularity also stemmed from the worldwide Autism Speaks initiative, Light It Up Blue. For additional information or to find out how to get involved, please visit the link below. #CelebrateDifferences #AutismAcceptanceMonth #AutismAwareness #Neurodiversity

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## What's New?

### Meet the ADDM Team

The Indiana Birth Defects and Problems Registry (IBDPR) program has been hard at work on their newest collaboration with the Centers for Disease Control and Prevention (CDC) on a four-year surveillance project, which was awarded April 2023. The project's team includes a project manager (Felicia Greer), project coordinator (Azza Hagel Agib), two chart abstractors (Antonia Smith and Shacoya Collins), and a data manager (Rohan Mehta).

Indiana is one of the newest sites within the Autism and Developmental Disabilities Monitoring (ADDM) Network, with the goal to understand the prevalence and characteristics of children with Autism Spectrum Disorder (ASD) and other developmental disabilities in diverse communities throughout the United States. The ADDM Network has been collecting and reporting ASD data from across the United States for more than 20 years.



This collaborative will aid in identifying changes in ASD occurrence over time, measure progress in early identification, and compare how common ASD is in different regions of the state, as well as nationwide. Ultimately, this work is aimed at improving health services and outcomes and expanding partnerships and collaborations through beneficial surveillance and transparency with the data to support individuals living with ASD and their families. The team is looking forward to collaborating with local ASD organizations throughout the month and for the remainder of the project.

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### NBS Referral Sheet

As part of the ongoing quality improvement efforts for Indiana newborn screening, the Newborn Screening Program continues to create new resources to be utilized by our partners to ensure all Hoosier infants are accurately referred and seen when in need of newborn screens and appropriate resources/follow-up care.

The most recent addition is the [NBS Referral Sheet](#), which should be used by any partner who sees walk-in patients who may be in need of an initial or repeat heel stick, CCHD, and/or hearing screens. The referral sheet should be completed by the referring entity and the birthing unit staff performing the necessary screens.

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## Did You Know?

### Metabolic Formula Program

Since July 1, 2023, the Indiana Metabolic Formula Program has increased access to specialized metabolic formula to our patients with inborn errors of metabolism living in Indiana. Many metabolic disorders, like PKU, require specialized formula as their primary medical treatment. These formulas are very expensive and have inequitable insurance coverage. These inconsistencies in coverage create a huge burden on the patient and families who have poor or no medical formula coverage. Due to these inequities, there has been a new focus on providing more access to these medically necessary, state mandated metabolic formulas to patients and families.

We are happy to report that to date we have assisted a total of 43 patients from both the IU Health Riley Metabolic Clinic and the Community Health Clinic where metabolic patients are managed. We have also created and awarded additional funding opportunities to the IU Health Riley Metabolic Clinic and Community Health Clinic to provide necessary diet related educational resources and specialty low protein to encourage continual diet education and support. This program continues to grow and evolve to meet the needs of the Indiana metabolic patients and community.

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