JOIN THE REGISTRY

Explore this resource and register today at nbsconnect.org

Your participation and contribution to the NBS Connect registry will help in understanding the long term outcomes of many of the less researched and very rare disorders, leading to better patient care and quality of life.

This project is funded by the Health Resources and Services Administration (HRSA) through the Southeast Regional Newborn Screening & Genetics Collaboration (SERC); and The National PKU Alliance.

EMORY UNIVERSITY SCHOOL OF MEDICINE

Department of Human Genetics
Division of Medical Genetics

Introducing NBS Connect
nbsconnect.org

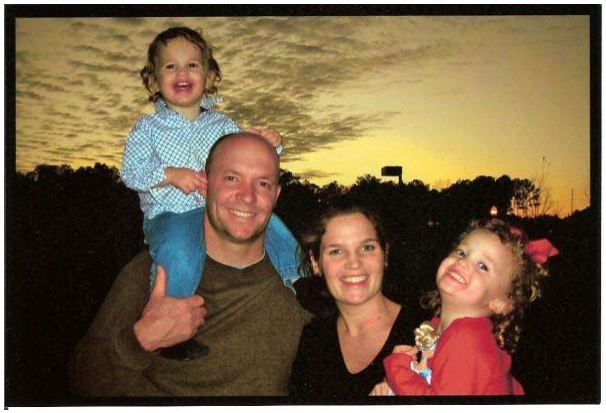
Contact Information

Yetsa Adadevoh
2165 N. Decatur Road
Decatur, GA 30033

Phone: 404-778-3353
Fax: 404-778-8562
Email:
coordinator@nbsconnect.org

EMORY UNIVERSITY DEPARTMENT OF HUMAN GENETICS: INTRODUCING THE NEWBORN SCREENING CONNECT PATIENT REGISTRY

nbs CONNECT



NBSCONNECT.ORG

A HRSA SUPPORTED PARTNERSHIP
GRANT #U22MC03960-04-00

About the Patient Registry

What is NBS Connect?

Newborn Screening (NBS) connect is a web-based self report patient registry. This resource is for those affected by certain disorders included in the newborn screening panel. The registry has been developed by national experts in the field of NBS disorders at the Department of Human Genetics at Emory University.

Extensive development of the registry will occur via a phased in approach using Phenylketonuria (PKU) as the model disorder, followed by other disorders in the newborn screening panel recommended by the American College of Medical Genetics (ACMG).

Getting Involved

Registering with NBS Connect and completing a Profile connects you to the latest news and information about inborn errors of metabolism and current clinical trials/research studies and allows you to learn more about the community. Registering also gives you access to information about care and treatment; genetic testing and nutritional services, and it enables us to tell you about upcoming research studies for which you may qualify.

Benefits to You

Active members of NBS Connect will benefit instantly in numerous ways:

- Gain access to a central hub of information allowing you to make more informed healthcare decisions.
- Access disorder specific educational materials, recipes, interactive health tracking systems, and connect with experts.
- Receive information about the latest research and clinical trials.
- Track your progress with other members of the community, and connect with other individuals who face the same daily challenges.

Who is managing the study?

- *Rani H. Singh, PhD, RD*: Lead Investigator
- *Yetsa Adadevoh, MPH*: Co-Investigator
- *Rita Underwood, MD, MPH*: Co-Investigator

NBSconnect.org

Our Mission

NBS Connect will serve as an internet-based support network for parents, guardians and individuals with inborn errors of metabolism. NBS Connect will capture and analyze information related to inborn errors of metabolism in an effort to assess gaps in service, access to care and to develop best standards of practice for clinical management and connect families to research opportunities. NBS Connect strives to improve the quality of care of individuals with inborn errors of metabolism (IEMs).