Welcome to the Newborns Screening Translational Research Network (NBSTRN), your number one source for facilitating your efforts to improve the lives of babies through research.

We are dedicated to building a community of clinicians, researchers, families and public health partners with a focus on:

- enabling clinicians, researchers, parents and patients to enter health information in our Longitudinal Pediatric Data Resource Center
- supporting the analytical and clinical validation of new technologies, new pilots studies and new knowledge discovery through secondary use of accumulated data.
- studying the ethical, social, and legal implications (ELSI) of newborn screening research and new knowledge discovery through secondary use of accumulated data.

Who Are We

"To improve the lives of babies together through research."

Contact Us

The NBSTRN is located at the American College of Medical Genetics

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Our History and Mission

Founded in 2008 as a key component of the Hunter Kelly Newborn Screening Program at the Eunice Kennedy Shriver National Institutes of Health (NICHD) through a contract with the American College of Medical Genetics and Genomics (ACMG), NBSTRN has grown into an international network involved in supporting cutting edge research, population based pilots and ethic, legal, and social (ELSI) discussions.

Our mission is to foster and grow our network and we are thrilled to help translate your research into real-world applications that will help save and improve the lives of newborns and children. We hope you will join our network so we can facilitate your important work in the field of newborn screening research.

Our Vision

- To facilitate ground-breaking research in newborn screening designed to discover new tests, conditions and treatments
- To foster a collaborative and integrative network of researchers, clinicians, families and public health partners to understand newborn screening outcomes
- To support pilots that inform the infrastructure, programming, and policies needed to expand and improve newborn screening

Our Values Statement

We, at NBSTRN, believe in the core values and principles for supporting our networks:

- Support success in partnerships and collaboration
- Effectiveness in innovation and teamwork
- Growth through knowledge and scientific discovery
- Integrity in all of our offerings to our network
- Commitment in nurturing our members in our network
- Competence in providing secure information systems
What's next for NBSTRN?

What We Can Do for You

By joining our network, we can help you:

- Build new connections and strengthen partnerships across government, academia, clinical care, public health and industry.
- Support data collection and data storage of phenotypic and genomic sequencing information for newborn screening research.
- Connect you with the resources and partnerships to support your initiatives in newborn screening research.
- Provide guidance for your research in ethical, legal, and social issues important in newborn screening research studies and pilot studies.
- Contribute to our growing Longitudinal Pediatric Data Resource (LPDR).
- Support the analytical and clinical validation of new technologies and track emerging findings from pilots in the NBS Research Repository.
- Enables new knowledge discovery through secondary use of accumulated data.

Join Our Network

How You Can Get Involved

Become a member of NBSTRN today!

Becoming a member will allow you to create an individualized collaboration space, access data, participate in private and public forum discussions, and conduct research studies using the tools, expertise and data stored in NBSTRN.

Visit us at www.nbstrn.org