



NBSTRN NEWSLETTER

Upcoming Meetings for
NBSTRN:

NBSTRN Network
Meeting

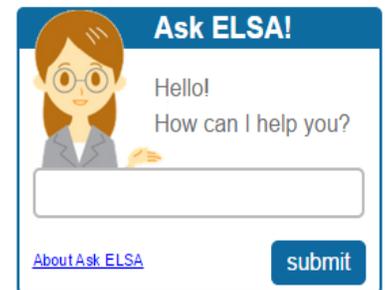
Sep 9- 11 Bethesda, MD

New Resource available through the NBSTRN!

In late February, the NBSTRN team launched our newest NBSTRN tool, called the ELSI Advantage. With the help of the NBSTRN Bioethics & Legal Issues workgroup, the ELSI Advantage was built. The ELSI Advantage is an ethical, legal and social issues resource for NBS researchers. Users will be able to find information on Return of Results, IRB's, NBS related FAQ's, and templates to customize your own Consent Forms.

We are very excited about this new NBSTRN tool. We hope they will provide useful information about various ELSI related issues and serve as a starting point for many research projects to come!

If additional ELSI related questions arise, just ask ELSA, our very own interactive avatar!



New Employee Announcement

We are pleased to announce that Helena Dessie is joining the NBSTRN staff to fill our new Administrative Assistant position. Helena is a recent graduate from Towson University in Baltimore, Maryland with a degree in Health Science and a concentration in Community Health. She is eager to begin pursuing a career in Public Health.

Prior to accepting this position, Helena has completed a five month internship with the Lupus Foundation of America, in Washington D.C. As the intern for the Lupus Foundation, she was able to contribute in a variety of ways by providing support and services for Lupus patients.

In addition to her administrative duties, Helena has also been a part of the planning and preparation process of various outreach activities. She has been involved in planning and preparing for health fairs, annual walks, yearly summits, and gala events.

We are so excited to have Helena join our team!





Spotlight on a Newborn Screening Researcher

Our spotlight researcher of the month is currently the Chief of the Evaluation Section of the Genetic Disease Screening Program at the California Department of Public Health (CDPH) and has held this position for over 20 years. He comes to the world of newborn screening via a B.S., M.S. and PhD in mathematics.

His time at CDPH has involved statistical monitoring of the existing newborn screening program as well as the prenatal screening program. He is also responsible for the development and implementation of new screening modalities. He uses his ability to determine ways in which information can be extracted from complex data sets to learn new information about rare conditions that impact newborns.

Read more and find out who the Researcher of the Month is by visiting: <https://www.nbstrn.org/about/spotlight-researchers>

If you have topics for inclusion in future newsletters, please let us know by emailing rfleming@acmg.net

The Longitudinal Pediatric Data Resource (LPDR) is now LIVE!



The Newborn Screening Translational Research Network (NBSTRN) developed the Longitudinal Pediatric Data Resource (LPDR) as a resource to facilitate the collection of longitudinal health information on individuals who have a genetic condition detected by newborn screening. The LPDR is a FISMA-compliant system comprised of: consensus-based, standardized common data elements (CDEs); electronic data capture; centralized data management; unified data representation and analysis; and case reporting.

Due to the strict security standards of the tools mentioned above, the LPDR is divided into two Levels of Access. Users must be registered and approved to access Level 1 resources and must go through a more comprehensive onboarding process for Level 2 access. The LPDR Level 1 website, is now live and many tools are available to users who are approved for access.

Please visit: <https://lptr-lvl1.nbstrn.org> to access this **new** and **improved** resource!