



NBSTRN NEWSLETTER

Mark your calendars!

NBSTRN Network
Meeting

September 9th-11th

Washington DC Area

NBSTRN Bioethics & Legal Issues Workgroup Update

The NBSTRN Bioethics and Legal (B&L) Workgroup met February 18th - 19th. Several goals were achieved at this meeting. The newly available ELSI Advantage resource (<https://www.nbstrn.org/resources/elsi-advantage>), which includes a consent form builder among other tools, was reviewed. A significant amount of time was devoted to working on the Longitudinal Pediatric Data Resource's (LPDR) data sharing agreement. Also discussed in depth was the impact of Section 12 of the Newborn Screening Saves Lives Reauthorization Act of 2014 (H.R. 1281) on newborn screening research. Michelle Lewis, co-chair of the B&L workgroup, represented the NBSTRN at the March 24-25 Secretary's Advisory Committee on Human Research Protections (SACHRP) meeting to introduce and discuss newborn bloodspot issues in relation to H.R. 1281. The B&L workgroup will meet again in person in the fall.

Steering Committee Meeting Update

The NBSTRN Steering Committee met immediately following the B&L workgroup meeting on February 19th-20th. This meeting's goal focused on reviewing NBSTRN's Year 2 accomplishments. To do this, recommendations from the Fall 2014 meeting were gone over and progress towards fulfilling NBSTRN's Statements of Work were reported on. Time was also spent generating survey questions for a needs assessment for the newborn screening community and looking over NBSTRN's ELSI Advantage, LPDR, and Virtual Repository for Dried Blood Spots (VRDBS) tools. The potential effects of H.R. 1281 were also discussed and a plan was proposed to assist the NBSTRN in considering this new law and its effects on the NBSTRN. Finally, new recommendations and additional goals were created for the rest of year 2 of the NBSTRN. The committee will meet again in person in the fall.





Spotlight on a Newborn Screening Researcher

May's spotlight researcher is an Assistant Professor in the Department of Bioethics at Case Western Reserve University, as well as the Assistant Director of the Center for Genetic Research Ethics and Law.

This mystery researcher has a background in genetic research as well as public health, completing his BS in Science and Technology Studies from Michigan State University, his MA in Bioethics from Case Western Reserve, an MPH in Health Education and Public Health Genetics from the University of Michigan and later receiving his PhD in Bioethics from Case Western Reserve University. He has researched issues in public health, genetics and bioethics but also has a strong focus on newborn screening research and has recently authored a publication that focused on parents' interest in whole-genome sequencing of newborns.

Read more and find out who the Researcher of the Month is by visiting:

<https://www.nbstrn.org/about/spotlight-researchers>

NBSTRN New Employee Announcement

Jennifer Loutrel graduated in 2009 from Drexel University in Philadelphia, Pennsylvania where she completed a bachelor's and a master's degree in Biomedical Engineering. She spent three years as a Data Integration Analyst with the Children's Hospital of Philadelphia, one year in industry in data management, and now joins ACMG on the NBSTRN team as a Data Integration Analyst. She is interested in expanding genomic technology for disease treatment and combining clinical data across entities to facilitate rare disease research.

