



NBSTRN NEWSLETTER

Mark your summer calendars!

The NBSTRN's Live Demonstrations of the VRDBS!

Upcoming dates:

Jun 19 at 2:00pm EST

Jul 17 at 2:00pm EST

Aug 21 at 2:00pm EST



NBSTRN Steering Committee's first Face-to-Face Meeting

As part of the renewed NBSTRN contract, the NBSTRN Steering Committee has been tasked to meet in-person twice a year for the next five years. We had a wonderful first in-person meeting on May 15th-16th in Bethesda Maryland. The group wrote a new mission statement, reviewed recommendations from the Bioethics & Legal Workgroup, received updates on the LPDR and VRDBS tools and made recommendations to the NBSTRN staff regarding next steps. The Steering Committee outlined priority items and made sixteen concrete recommendations to the NBSTRN staff regarding the maintenance and enhancement of existing NBSTRN tools for researchers and the potential development of new resources for the NBSTRN.





Spotlight on a Newborn Screening Researcher

The NBSTRN's June Spotlight Researcher has focused her research on Inherited Metabolic Diseases. She is currently the Director of Mount Sinai's Program for Inherited Metabolic Diseases where she oversees testing, diagnostic evaluation, counseling and long-term medical management of referred infants. Her program is one of the largest diseases treatment programs in the US.

Our researcher received her B.S. from Cornell University and then her M.D. from New York University in 1992. After that she completed her residency in pediatrics and a fellowship in human genetics at Mount Sinai Hospital. She has been a faculty member of Mount Sinai since 1997 holding various academic appointments throughout her time there. This doctor is board certified in Biochemical Genetics, Pediatrics and Clinical Genetics. She is an avid spokeswoman on newborn screening at conferences and lectures on newborn screening.

Find out who it is by visiting: <https://www.nbstrn.org/about/spotlight-researchers>

NBSTRN Bioethics and Legal Issues Workgroup Face-to-face Meeting

The NBSTRN Bioethics Workgroup meeting convened on May 14th-15th with a goal to address the ethical, legal and social implications (ELSI) of all NBSTRN activities and to make ELSI recommendations to the Steering Committee. As part of the renewed NBSTRN contract that was awarded last September, the NBSTRN must establish, maintain and administer a web based interactive resource related to the ethical, legal and social implications (ELSI) relevant to Newborn Screening investigators. The Bioethics Workgroup took its first steps towards being the leading workgroup behind this ELSI resource by discussing where there are unmet needs in the newborn screening research community and their plans to address those needs. The Bioethics Workgroup decided on their scope of work for the upcoming year and made fourteen ELSI related recommendations that they passed on to the Steering Committee for review. We look forward to spending the next several conference calls continuing this dialog. In addition, the group has outlined a plan for updating existing resources available on the NBSTRN.org website.