



NBSTRN NEWSLETTER

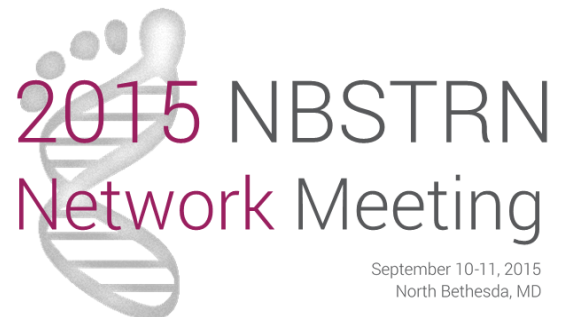
2015 NBSTRN Network Meeting

We'd like to extend a warm "thank you" to all who participated in making this meeting a successful event! We had a wonderful turn out for our Network Meeting on September 10th and 11th. Of the 115 people registered, 98 were able to join us in person.

On our first day we learned from grantees using tools and resources available through the Newborn Screening Translational Research Network (NBSTRN), and had the opportunity to learn about ongoing and future pilots in newborn screening. In addition, we heard presentations on the ethical and legal implications associated with newborn screening after the enactment of the Newborn Screening Saves Lives Reauthorization Act of 2014. On our second day, we had the opportunity to learn about new topics in the public health and newborn screening field as well as new initiatives from federal partners.

Overall, it was a very productive day and a half and will help us move forward with new ideas and reasons to support NBSTRN researchers. We look forward to continuing our efforts in perfecting our tools and supporting newborn screening researchers.

In order to improve our efforts, we've developed a brief feedback survey. Please visit: <https://www.surveymonkey.com/r/NBSTRNNetworkfeedback> to provide feedback on the Network Meeting.



September 10-11, 2015
North Bethesda, MD

Upcoming Meetings for NBSTRN:

2015 ASHG Annual Meeting

Oct 6-10, Baltimore,
MD

NORD Rare Disease and Orphan Products Breakthrough Summit

Oct 21-22, Arlington,
VA





Spotlight on a Newborn Screening Researcher

Our spotlight researcher of the month is currently the Director of the National Newborn Screening and Global Resource Center. He retired as Professor in the Department of Pediatrics at the University of Texas Health Science Center at San Antonio (UTHSCSA) in 2013 and is currently serving as an Adjunct Professor in the Department of Pediatrics.

Prior to joining NNSGRC, this researcher previously worked at the Texas Department of Health Bureau of Laboratories for over 28 years, where he served as the Director of the Chemical Services Division. As the Director, he was in charge of newborn screening and other biochemical screening programs. He also served as the Director of the Texas Department of Health laboratory project which helped provide laboratory screening services to individuals with Medicaid. Furthermore, he is also a founding member and a Past President and Secretary of the International Society for Neonatal Screening (ISNS). In 2000, he was awarded the Robert Guthrie Award, which honors newborn screening researchers for their outstanding contributions to the newborn screening world.

To find out more about this researcher's work and involvement in NBS, visit:

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

NBSTRN NBS Researcher Needs Assessment

For the last 50 years, newborn screening programs have been a critical part of the public health infrastructure, decreasing morbidity and mortality for dozens of specific conditions. Newborn screening research is necessary to continue and improve these NBS programs. The NBSTRN has worked for the last seven years to build and develop tools and resources that a researcher can access to improve the health outcomes of newborns with genetic or congenital disorders.

The NBSTRN is conducting a brief needs assessment among newborn screening researchers to ensure that we are meeting the researcher's needs. This needs assessment will be distributed at national meetings and conferences but we encourage you to take 5-10 minutes of your time and fill out the [needs assessment](#).

If you have topics for inclusion in future newsletters, please let us know by emailing

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NBSTRN
Newborn Screening
Translational Research
Network