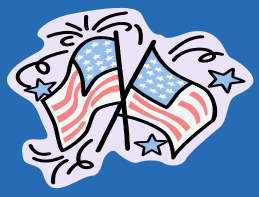

MARK YOUR CALENDARS!

NBSTRN
NETWORK MEETING
September 22nd-24th, 2014
Bethesda, MD

September 22nd-23rd, 2013

Bethesda, MD

Registration Information will be coming soon!

Newborn Screening Translational Research Network

July 2014

NBSTRN NEWSLETTER

The NBSTRN's Virtual Repository of Dried Blood Spots' Upcoming Public Training Webinars

This July, we are excited to highlight one of our three newborn screening research tools. The NBSTRN's Virtual Repository of Dried Blood Spots (VRDBS) holds de-identified data of over 2.9 million dried blood spots. Once registered in the VRDBS, an investigator can locate and request specimens from the participating states. All dried blood spots are controlled by the state public health programs and requests for dried blood spots are reviewed by state newborn screening programs though the VRDBS system.

Public training webinars are held on the third Thursday of the month at 2:00pm EST. The next public training webinars will be held on:

Jul 17 **Aug 21** **Sep 18** **Oct 18** **Nov 20**

These one hour training sessions will demonstrate a variety of features available to investigators. At the remaining of the hour participants will have the opportunity ask direct questions to the presenters. The webinars are intended for potential investigators, but anyone is welcome to join to learn more about VRDBS. To register for the VRDBS or to find out more about this tool please visit, the VRDBS landing page on NBSTRN.org.

VRDBS
Virtual Repository of Dried Blood Spots

NBSTRN is funded by a contract from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Institutes of Health to the American College of Medical Genetics and Genomics (#HHSN275201300011C).

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

Spotlight on a Newborn Screening Researcher

The NBSTRN July Spotlight Researcher has focused her clinical research on the genetic causes of hearing loss, Native American myopathy, constitutional chromosomal abnormalities and newborn screening for genetic disorders. This researcher completed her undergraduate coursework at Cornell University in Biology. After that, she completed her masters in human genetics from Sarah Lawrence College and earn her medical degree from the Medical College of Virginia (Virginia Commonwealth). After receiving her medical degree, she completed a pediatric residency Children's National Medical Center in Washington, DC.

She is currently a professor of pediatrics and genetics at the University of North Carolina and member of the Carolina Center for Genome Sciences where she is a principal investigator on a study looking at the parental attitudes genetic services for of children with early-onset hearing loss. At UNC she is working on a grant which will sequence the genomes of 400 infants to determine what useful clinical data can be found through tests. Alongside this effort, this researcher's team will help develop educational and consent tools to determine how to best educate parents and physicians about tests.

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

Congratulate the NBSTRN Facebook page!

The Newborn Screening Translational Research Network's (NBSTRN) Facebook page reached over 200 "likes" this June. We are always glad to welcome new friends who are excited to be updated on the current newborn screening legislative bills being passed in their states, newborn screening research findings, and information on upcoming webinars for the newborn screening research community.

To get involved in the newborn screening research community, feel free to "like" our Facebook page and be updated with the most current news and events.

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Newborn Screening Translational Research Network

NBSTRN is funded by a contract from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Institutes of Health to the American College of Medical Genetics and Genomics (#HHSN275201300011C).