



NBSTRN NEWSLETTER

Mark your summer calendars!

The NBSTRN's Live
Demonstrations of the
VRDBS!

Upcoming dates:

Jun 18 at 2:00pm EST

Jul 16 at 2:00pm EST

Aug 20 at 2:00pm EST

Visit NBSTRN.org to
register for a demo!



Save the Date

NBSTRN Network Meeting
September 10-11, Washington DC

The NBSTRN's 2015 Network Meeting will be held in the Washington DC area, September 10th (8:30am–5:00pm) and 11th (8:30am–12:00pm). Please look for important registration information which will be available soon.

The Virtual Repository of Dried Blood Spots compliant with NBS Saves Lives Act

The VRDBS is fully compliant with the new regulations mandated by the Newborn Screening Saves Lives Reauthorization Act (H.R. 1281). Uploads from participating states are being accepted if the dried blood spots were collected prior to March 18th, 2015, the date that corresponds to the end of the 90 day enactment period of the law. The VRDBS will continue to maintain operations and assist researchers in any of their newborn screening research related efforts.



Spotlight on a Newborn Screening Researcher

Our spotlight researcher of the month is currently the Fellow Program Chair and Distinguished Fellow in early childhood development at RTI International. He is well known as an expert for young children with disabilities, specializing in children with fragile X syndrome.

Prior to joining RTI, this mystery researcher spent over 27 years working as the Director of the Frank Porter Graham Child Development Institute and as a W.R. Kenan, Jr. Distinguished Professor of Education at the University of North Carolina at Chapel Hill. His research has focused on children with fragile X syndrome, a genetic condition that causes a range of developmental problems including learning disabilities and cognitive impairment. He brings his extensive background to current newborn screening grants and studies. Currently, he is planning a multi-state study that screens a large number of newborns for fragile X syndrome. The study will serve as a prototype for addressing public concerns as more genetic disorders are identified that may not have known medical cures.

Read more and find out who June's spotlight Researcher is by visiting:

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

NICHD Solicitation Announcement

On May 20th, 2015 the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) issued an official solicitation notice requesting proposals for Newborn Screening Pilot Studies. The purpose of this acquisition is to create a pool of high throughput newborn screening laboratories with the capacity to screen a large number of newborns in relatively short periods of time that are representative of various regions of the United States. The solicitation offers the potential to create an MPS1 Pilot Study that will support the development, implementation and proof of concept of new technologies in newborn screening for MPS1.