



# NBSTRN NEWSLETTER

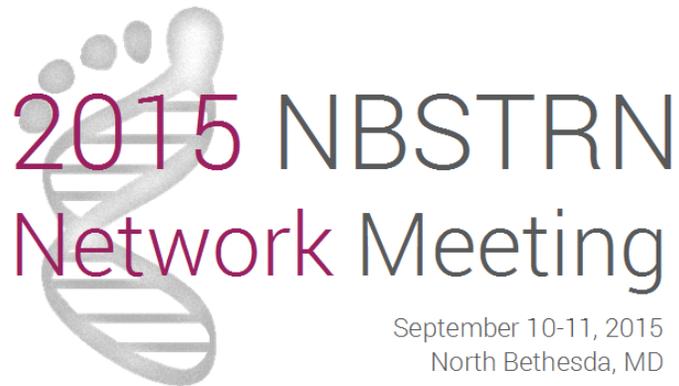
## Where will you see us next?

**NBSTRN Network Meeting**

**Sep 10-11, Bethesda, MD**

**2015 ASHG Annual Meeting**

**Oct 6-10, Baltimore, MD**



September 10-11, 2015  
North Bethesda, MD

The NBSTRN will be hosting its annual Network meeting in September to share progress and outcomes for ongoing and future newborn screening (NBS) research and to provide a forum for understanding the ethical and legal issues associated with doing NBS research. We plan to have two panel discussions on the afternoon of the 10th: one addressing the changes to the research landscape brought on by the Newborn Screening Saves Lives Reauthorization Act, and another discussing the newborn screening informed consent atmosphere. Additionally, our federal partners will speak about the guidelines and laws that affect the NBS research community.

We invite you to register to attend the meeting which will be held on September 10<sup>th</sup> (8:30am to 5:00pm) and September 11<sup>th</sup> (8:30am to noon) located at the Bethesda North Marriott Hotel and Conference Center, 5701 Marinelli Road, North Bethesda, MD.

Please register accordingly as a NBSTRN Workgroup member, meeting speaker, or general attendee on the:

[NBSTRN Network Meeting Registration page.](#)

We look forward to your presence and participation at the meeting.





## Spotlight on a Newborn Screening Researcher

July's spotlight researcher of the month is currently the Program Manager for the Newborn Screening Laboratory in the New Jersey Department of Health. He is well known in the newborn screening community for his continued efforts in enhancing systematic quality improvement to the newborn screening system.

His time at the New Jersey Department of Health has helped enhance systematic quality improvement by facilitating and executing new technologies as the New Jersey Department of Health underwent a physical move to a new testing facility. Apart from his daily responsibilities for the screening results of newborns, he also serves as Chair of the Steering Committee for the APHL's Newborn Screening Technical assistance and Evaluation Program (NewSTEPS).

In 2012 this mystery spotlight researcher showed exceptional leadership when he successfully implemented emergency procedures to maintain transportation of specimens during Hurricane Sandy.

To find out who the Researcher of the Month is, visit:

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

## In the News: NBS Saves Lives Reauthorization Act

When the Newborn Screening Saves Lives Act was reauthorized in late 2014 it contained some new language. The law now requires consent for federally funded research on newborn screening dried blood spots, even after they have been de-identified.

On May 15, an article published in Science, titled "Newborn screening collides with privacy fears" quoted Michael Watson, PhD, FACMG, ACMG's Executive Director and PI for the Newborn Screening Translational Research Network (NBSTRN). Dr. Watson was quoted saying that since the new law was enacted in March 2015, the NBSTRN's virtual dried blood spot repository continues to be used for research but currently it is only accepting spots collected prior to the reauthorization going into effect. To read the whole article, [click here](#).

In the meantime, the Office for Human Research Protections, in the Department of Health and Human Services, is drafting guidelines on the law and plans to define what qualifies as newborn screening research.



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