



Upcoming Meetings for NBSTRN:

AMCHP 2015

Jan 24-27,
Washington DC

LSD World

Symposium
Feb 9-13, Orlando, FL

Clinical Integration Group Face-to-Face meeting

Feb 2-3, Bethesda,
MD



NBSTRN NEWSLETTER

The Virtual Repository of Dried Blood Spots reaches 3 million dried blood spots!

As of January 2015, the VRDBS has 3,030, 060 dried blood spots available for newborn screening researchers. The VRDBS is an open-source, web-based tool that enables state program personnel to control and manage access to dried blood spot specimens for newborn screening related research.

De-identified data from dried blood spots (DBS) from the four participating states (California, New York, Michigan and Iowa) is centrally located, while the specimens themselves remain in their state of origin. Each state that participates in the VRDBS is asked to provide basic, de-identified, HIPPA compliant data associated with the DBS that they have included in the VRDBS. To maintain the security of our system, only approved investigators with genuine newborn screening related research interests are given access to the Virtual Repository. Investigators are required to upload their CV or resume, research proposal, funding and IRB approval information in order to complete the request process.

If you are an investigator who is interested in learning more about the VRDBS, please join us for the NBSTRN's January training webinar on January 15th at 2:00pm EST. You can find registration information for these training webinars on the NBSTRN.org. If you would like to find out more information about the VRDBS, you can visit the [VRDBS landing page](#) on the NBSTRN.org website.

VRDBS 
Virtual Repository of Dried Blood Spots



Spotlight on a Newborn Screening Researcher

January's spotlight researcher has been a professor in the departments of immunology and pediatrics at the University of California in San Francisco as well as Director of the Pediatric Clinical Research Center in the UCSF Clinical and Translational Research Institute's Clinical Research Services Division since 2006.

She has an extensive research background, completing her BA and MA from Harvard University as well as receiving her medical degree from Harvard Medical School. After medical school, she went on to complete a pediatric residency and an infectious disease fellowship from St. Louis Children's Hospital at Washington University. In 1993, she became senior staff physician at the W.G. Magnusen Clinical Center at the National Institutes of Health (NIH) as well as head of the Immunologic Disease Section at the National Human Genome Research Institute (NHGRI). In 1997, she became Chief of the Genetics and Molecular Biology Branch at NHGRI.

Read more and find out who the Researcher of the Month is by visiting:

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

The Newborn Screening Saves Lives Reauthorization Act

We are excited to hear that the Newborn Screening Saves Lives Reauthorization Act (HR # 1281) was passed by the Senate on December 8th, 2014, by the House of Representatives on December 10th, 2014, and became law on December 18th, 2014, after being signed by the President .

The reauthorization act reauthorizes and revises authorities for newborn screening activities carried out by the Department of Health and Human Services. Through the fiscal year 2019, it will extend the grant program for screening, counseling and other services related to heritable disorders that can be detected in newborns. To learn more about the Reauthorization act, we encourage you to visit the [March of Dimes](#) or the [statement](#) given by the Press Secretary of Bills signed into law.



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