

Where can you see us next?

Pediatric Academic Societies Meeting
April 28-May 1, 2012
Boston, MA

2012 Annual Research Meeting
Academy Health
June 24-26, 2012
Orlando, FL

NBSTRN Workgroup Meetings....

NBSTRN IT Workgroup Meeting
April 5-6, 2012
Boston, MA

NBSTRN Standing Committee Meeting
May 16, 2012
Washington, DC

NBSTRN Bioethics & Legal Workgroup Meeting
June 5-6, 2012
Chicago, IL

NBSTRN NEWSLETTER

April 2012



Providing Newborn Screening Specimens for Research: Legal Issues Faced by State Health Departments Webinar Series

States that store and provide residual dried blood spots (DBS) for secondary uses, or are considering storage and secondary uses, may face an array of legal issues. This webinar series will cover these legal issues – and related ethical issues – concerning secondary uses of DBS and associated data.

This webinar series is intended for public health attorneys, newborn screening programs and laboratories, institutional review boards, HIPAA privacy boards, privacy officers, researchers, and others who have interest in legal and ethical issues related to secondary uses of residual DBS.

*The log-in password is "health" for all 6 webinars.

Date	Topics	Registration Link
April 26, 2012 1:00pm EST	Introduction	Click Here
May 31, 2012 1:00pm EST	Ownership and control of specimens	Click Here
June 28, 2012 1:00pm EST	Protection of privacy	Click Here
July 26, 2012 1:00pm EST	Protection of human research subjects	Click Here
August 30, 2012 1:00pm EST	Ownership and control of research results	Click Here
September 27, 2012 1:00pm EST	Summary of core issues	Click Here

Jointly presented by the NBSTRN, The Network for Public Health Law, the National Newborn Screening and Genetics Resource Center (NNSGRC), and the Association for Public Health Laboratories (APHL)

Raising the Bar...



The NBSTRN Coordinating Center is currently managing multiple sub-contracts and supporting multiple research grants. As a contractor to NICHD we are required to follow certain guidelines and best practices for building information technology tools and infrastructure. A key guideline is the Federal Information Security Management Act (FISMA) that requires the ACMG to perform a Risk Assessment and assign a Security Category to each subcontract and grantee project. To date, the ACMG/NBSTRN has five risk-based information security programs underway: 1) Region 4 Stork (R4S); 2) Virtual Repository of Dried Blood Spots (VRDBS); 3) NBSTRN.ORG website; 4) Long-Term-Follow-Up Effort (LTFU); and 5) the ACMG's Virtual Server Cluster. Of these five, four are categorized as a "Low-risk" and one, (LTFU), is assessed to be "Moderate-risk" due to personal health information. It is this "Moderate-risk" that motivated the ACMG to "raise the bar" in order to meet what the National Institute of Standards (NIST) NIST refers to as the "high-water-mark".

These NIST guidelines establish risk-based security controls so that agencies and contractors can implement consistent and cost-effective security controls across the information technology infrastructure. Special attention is devoted to ensuring that consistent, comparable and repeatable security control assessments underpin operational and administrative policies, plans and procedures enterprise wide. The ACMG has created a FISMA Control Board with volunteers recruited from the NBSTRN Workgroups to advise and evaluate how the FISMA-Moderate System Security Plan is being developed for the LTFU project.

The goal is to deploy information systems that are complete and reliable so that ACMG/NBSTRN subcontractors and collaborating grantees have an operational framework that affords more informed security decisions. If you have any questions about FISMA or our plans for security please contact Bruce Bowdish at bbowdish@acmg.net.

VRDBS Update

On January 19, 2012, the NBSTRN and 5AM Solutions provided the first public training and demonstration of the VRDBS to registrants ranging in background from academia, state and federal government, and domestic and international hospitals. This first webinar, in a series of monthly training throughout 2012, covered VRDBS basic features for investigators including: an overview of how to use the site, how to register for an account, submit questions to states, and request letters of support. The focus of the webinars will alternate monthly to provide training on functionality for investigators and state users. For more information and to register for future webinars see the NBSTRN website: <http://nbstrn.org/research-tools/virtual-repository-of-dried-blood-spots/demo-dates>.

In other VRDBS news, in accordance with Health and Human Services final data collection standards for Race and Ethnicity as required by Section 4302 of the Affordable Care Act, the VRDBS database and data import process have been updated to accommodate for the data standards. For more information about these data standards see the HHS Press Release: <http://www.hhs.gov/news/press/2011pres/10/20111031b.html>.



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