

Where can
you see us
next?

Public Health &
Law Conference
October 10-12,
2012
Atlanta, GA

Annual Meeting
of the American
Society of Hu-
man Genetics
(ASHG)
November 6-
10, 2012
San Francisco,
CA

PRIM&R Ad-
vancing Ethical
Research Con-
ference
December 4-6,
2012
San Diego, CA

**NBSTRN
Workgroup
Meetings....**
NBSTRN Bio-
ethics and Le-
gal Issues
Workgroup
Meeting
October 17-18
Washington,
DC

NBSTRN Stand-
ing Commit-
tee Meeting
December 6-7
Washington,
DC

NBSTRN NEWSLETTER

October 2012



N B S T R N
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

NBSTRN Unveils New, First-of-its-Kind Virtual Repository For Newborn Screening Researchers: New System Will Save Lives and Improve Newborn Testing

After one-and-a-half years of intense development, end-user testing, a successful pilot, and through a contract to the American College of Medical Genetics and Genomics (ACMG) from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, the **Newborn Screening Translational Research Network (NBSTRN)** Coordinating Center has developed a centralized, web-based virtual repository of newborn dried blood spots (DBS) as an indispensable tool for newborn screening researchers. This innovative and invaluable new system presents secure information about stored specimens in participating states, providing newborn screening researchers with a simultaneous cross-state view of available dried blood spots.

These dried blood spots are a result of a tiny heel stick of blood taken from newborns shortly after birth. The newborn screening program in the United States has been hailed as one of the most valuable public health programs in the past 10 years and has saved thousands of lives and saved even more children from lives of severe disability or devastating illness. The blood spots are used not only to screen babies for debilitating or life-threatening diseases but also then are used to make sure that the newborn screening tests are as accurate as possible and to develop tests for more conditions. "Everyone wants to reduce false positives and also to use these dried blood spots in a secure, anonymous, privacy-protected way to come up with the most accurate tests in the future for these very rare, serious conditions. Without research on dried blood spots more people will die or be affected by these very serious, terrible conditions," said Michael S. Watson, MS, PhD, Executive Director of the American College of Medical Genetics and Genomics and Principal Director of the NBSTRN Coordinating Center.

This new, first-of-its-kind Virtual Repository of Dried Blood Spots (VRDBS) supplies registered researchers with centralized access to de-identified DBS nationwide, thereby providing the opportunity to easily search for and request specimens, and subsequently acquire the DBS (if approved by the state holding the specimens) from diagnosed positives and the general population. All information is centrally located to ensure fast and secure search response times, while the DBS specimens themselves remain at the state newborn screening programs. "This is the only general population-wide resource of its kind and it is what is needed to make newborn screening better and to assure the best outcome for children now and in the future", said Amy Hoffman, MPH, Project Manager of the NBSTRN.

"This new virtual repository of newborn screening dried blood spots is especially important because it provides scientific investigators unparalleled access to materials essential for research while ensuring that the confidentiality, upon which the highly successful newborn screening programs are based, is safeguarded," said Barry Thompson, MD, FACMG, Medical Director, ACMG/NBSTRN.

The NBSTRN VRDBS will:

- Automate the specimen request process, thereby expediting the search and request process overall;
- Provide researchers with a view of de-identified information on the DBS stored in all participating states;
- Provide insight into the data elements that each state collects (important for early stage investigators);
- Provide a single-point to browse the rules and regulations of each state, so that researchers can know what will be required of them to interact with the state; and
- Provide a secure, web-based interface for state NBS programs to share information more easily with the research community.

The VRDBS meets all data security requirements of the Federal Information Security Management Act (FISMA) and includes basic security features such as secure user ID and password, session timeout, role-based security administration and access, and secure data transfer. The NBSTRN Coordinating Center contracted with SAM Solutions, Inc. to create this web-based resource. Each state that participates in the VRDBS is asked to provide basic, de-identified data without personal health information associated with the DBS they wish to include in the VRDBS. The NBSTRN VRDBS protects privacy and maintains the security of the information while meeting the very serious need to improve science and technology to save lives now and in the future.

The NBSTRN website (www.nbstrn.org) is the information portal for accessing all of the services available to investigators including the new Virtual Repository of Dried Blood Spots. In addition to the VRDBS, the site includes helpful information for parents and the general public about newborn screening and the latest newborn screening-related news and updates.

Have you "Liked" us on Facebook?

With the recent release of the Virtual Repository of Dried Blood Spots, our social media has exploded! We are so excited to share our mission, tools, and upcoming events through these wonderful tools. For the month of September, in honor of Newborn Screening Awareness Month we featured heartwarming success stories, a variety of tools for parents, and NBS facts. We are excited to continue with these and other interesting facts as we celebrate 50 years of NBS throughout the year.

Have *you* liked us on Facebook? If not, you are missing out on the up-to-date news and alerts.

2013 Workgroup Meetings

Please mark you calendars with these *TENTATIVE* dates. We are hoping to have them finalized and sent out to individual workgroups soon. All meetings will be held in the Washington, DC area.

- Laboratory Workgroup Meeting: March 7-8, 2013
- Clinical Centers Workgroup Meeting: April 3-4, 2013
- Standing Committee: April 21-22, 2013
- NBSTRN Planning Meeting: April 22-23, 2013
- Bioethics & Legal Workgroup Meeting: June 6-7, 2013

**Please let us know if there are any conflicts that we should be aware of by notifying Irina Smotrich at ismotrich@acmg.net.

VRDBS Video Released

After months of hard work, the NBSTRN team along with members from our Standing Committee and 5AM Solutions, can finally announce the release of the Virtual Repository of Dried Blood Spots video. The video is a short 3 minute overview of the NBSTRN and the VRDBS. It is intended to be a short piece that targets NBS researchers and any questions that may arise from the general public. A second video describing how easy the VRDBS is to use will be released at the end of October.

The VRDBS video is available on the NBSTRN website and the various NBSTRN social media outlets. In addition, the video has been distributed to the NBS list-serve and will be available at the NBSTRN booth while attending various professional meetings (see previous page).

Let us know what you think by emailing nbstrn@nbstrn.org!



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