

Where can you see us next?

PRIM&R

December 2-4, 2011
National Harbor, MD

2012 Annual Research Meeting-
Academy Health
June 24-26, 2011
Orlando, FL

Do you know of a good venue for a presentation from the NBSTRN?

CONTACT US!

NBSTRN Workgroup Meetings....

NBSTRN Standing Committee Workgroup Meeting December 1-2, 2011

***FLIP OVER the page for the 2012 NBSTRN Meeting calendar**

NBSTRN NEWSLETTER



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December 2011

Welcome

Welcome to our December NBSTRN Newsletter issue! The NBSTRN is excited to update you on the 2012 workgroup meeting calendar, the VRDBS, NBSTRN.org, and the Clinical Centers workgroup.

NBSTRN State Profile:

In cooperation with the Association for Public Health Laboratories (APHL) and the National Newborn Screening and Genetics Resource Center (NNSGRC), the NBSTRN has collected specific information about each of the states' newborn screening program and has compiled it in the NBSTRN website in one, easy to access, resource. This information includes state program contact information, dried blood spot retention, storage, and use information, state-specific IRB protocols, and other information pertinent to newborn screening related research. All information is being updated now and we look forward to having it completed in December. If there are other data fields you feel would be useful for this resource please let us know.

Region	State NBS Program Link	Blood Spot Retention Time
Storage Condition	Approx Annual Births	Approx Ethnic Distribution
Requirements for Adding New Test to Panel	Process for NBS Expansion	Requirements for NBS Expansion
Informed Consent Required for Research	Multi-State Research Policies	State Contact Info (Lab and FU)
NBS Card Image		

For States Participating in the VRDBS:

Years of Data in VRDBS	Recovery Fees	MTA Info and Links
IRB Info and Links		

NBSTRN 2012 Meetings—Mark YOUR Calendars!!!

Please mark you calendars with the dates below. All locations are tentative and will be finalized as the meeting dates approach.

March 1-2 – Labs WG, Phoenix, AZ

April 5-6 – IT WG, Boston, MA

May 16 – Standing Committee, Washington, DC

June 5-6 – Bioethics WG, Chicago, IL

September 27-28 – Labs WG, New Orleans, LA

October 4-5 – IT WG, Washington, DC

October 17-18 – Bioethics WG, Washington, DC

December 6-7 – Standing Committee, Jacksonville, FL

We would LOVE your feedback on the NBSTRN web-site! Go to <http://www.NBSTRN.org> and take our 3 minute survey, conveniently located on the homepage!



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VRDBS Update

The VRDBS pilot is now scheduled to start March 2012. Currently four states are participating in the pilot, including: New York, Michigan, California, and Iowa. States are working on several on-boarding activities such as Data Exchange Agreements, condition mapping, and test file generation. Preparations are underway to provide User Guides for all types of users including: Investigators, State Administrators, State Lab Technicians, and NBSTRN Administrators. In addition, in-person and virtual training courses will be provided through out 2012. The VRDBS demo site continues to provide updated software based on functional assessment feedback, such as enhanced search capabilities, progress bar, and request submission. Check out these changes and more in the VRDBS demo site:

<https://nbstrn-demo.5amsolutions.com/tissuelocator-web/browse.action>.

Clinical Centers Update

(Co-Chaired by Susan Berry, MD & Kathryn Hassell, MD)

The Clinical Centers Workgroup has been working with the NCC LTFU Data Workgroup to define the information that is important to collect across the lifespan for individuals diagnosed with a condition on the Recommended Uniform Screening Panel (RUSP). This joint effort is also considering candidate conditions for newborn screening. It is expected that this information will improve scientific understanding of these diseases and facilitate the development of new screening technologies, novel treatments and improved management strategies. Oral and poster presentations describing this effort and introducing the data sets have been given at several professional meetings this year. The Clinical Centers Workgroup is now assisting with the creation of a data capture tool and data management system. A key part of this effort will be defining guidelines regarding data capture and use across key stakeholders including researchers, grantees, public health teams and clinicians.