

Where can
you see us
next?

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

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

NBSTRN Workgroup Meetings....

NBSTRN Stand-
ing Committee
Meeting May
16, 2012
Washington, DC

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

NBSTRN Labora-
tory Workgroup
Meeting
September 27-
28
New Orleans, LA

NBSTRN NEWSLETTER



N B S T R N
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

May 2012

Welcome

Welcome to the May addition of the NBSTRN Newsletter. We are excited to update you on the Virtual Repository of Dried Blood Spots along with other events and news. As Always we appreciate any and all feedback, please let us know what you think by taking our two minute survey on our website, <http://www.NBSTRN.org>.

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 one, easy to access, resource on <http://www.nbstrn.org>. In the last several months we altered the state profile to make more information available for the states that are participating in the VRDBS pilot. This additional information will aid investigators in their DBS search. If there are other data fields you feel would be useful for this resource please let us know.

The State Profiles include:

- Newborn screening program contacts
- Residual dried blood spot retention, storage and use data
- State-specific IRB protocol
- Other information pertinent to newborn screening related re-
search

NEW Specific information for those states participating in the VRDBS include:

- Years of data included in the VRDBS
- Frequency of upload of data
- State-specific IRB and MTA information
- Fees for specimen recovery, processing and shipping
- Additional review or steps needed outside of the VRDBS

VRDBS Pilot Begins

The Virtual Repository Pilot is now underway with de-identified data from New York and Iowa and soon to include data from Michigan and California. This is a controlled pilot—no access to the general public. We plan to be in production—access to the public— in September. If you or someone you know is interested in being a pilot investigator and actually using the VRDBS to obtain specimens for research please let us know. Contact Amy Hoffman at ahoffman@acmg.net.

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

The NBSTRN, APHL, NNSGRC, and The Network for Public Health Law are sponsoring a webinar series which will cover legal issues – and related ethical issues – concerning secondary uses of DBS and associated data. The 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. We are excited to announce that **continuing education credits are now available** for this series. Please contact Irina Smotrich for more information at ismotrich@acmg.net.

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

Date	Topics	Registration Link
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

VRDBS Update

VRDBS State training has begun! We are excited to announce that the first two training sessions are complete. On April 16th two members from the 5AM team and Amy Hoffman went to Lansing, MI to meet with members from the Michigan Health Department and representatives from the Michigan BioBank. On April 30th 5AM and NBSTRN team members went to Iowa to review the VRDBS workflow, demo the system and practice scenarios. We are excited to continue these state trainings with one scheduled for May 2nd in Albany, New York. These trainings prove to be extremely helpful for all of the VRDBS participants and we are thrilled to work with Michigan, Iowa, New York, and California throughout our pilot process.

If you want to find out more information about the progress of our State training, feel free to email Amy Hoffman at ahoffman@acmg.net.



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