

Where can you see us next?

AMCHP Annual Conference
February 11-14, 2012
Washington, DC

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....

*2012 Meeting

Calendar is out!!!

NEW!

*Data Access Meeting- February 16-17, 2012

Washington, DC

NBSTRN NEWSLETTER



NBSTRN
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

January 2012

Welcome

We hope everyone had a wonderful holiday season, we are very excited to kick off this year with new projects and new ideas for existing projects. For the first few months, we hope to continue our focus on marketing the NBSTRN and the Virtual Repository of Dried Blood Spots. The NBSTRN team is excited to announce that we have developed a set of **Executive Slides**. These may be modified to your needs and used to present about the NBSTRN to your colleagues or to others in professional meetings, Grand Rounds, or other venues. We believe that together, we can spread the value of the NBSTRN quicker and more effectively. The slide set is available on our Workgroup Wiki. We want to keep track of all presentations so please let us know if you used the slide set. As always, we would love your feedback ! Please send comments to Amy Hoffman at ahoffman@acmg.net.

Capturing Data Across the Lifespan to Improve Scientific Understanding

In the August newsletter we updated you on our effort to define a data set of clinical information to serve as a resource for researchers, clinicians and public health. We are now beginning work on the next step of developing a tool designed for clinicians to collect the data. This work is being led by Dr. Peter White and his team at the Children's Hospital of Philadelphia through a subcontract administered by the NBSTRN. The data capture tool is being developed using Research Electronic Data Capture (REDCap). Since its introduction into the academic research community in 2007, the REDCap (Research Electronic Data Capture) data management system has quickly emerged as an academic standard for investigator-driven research data management, with over 175 institutions and nearly 5,000 research studies now using the tool. Brief overviews of the REDCap database were presented in December. If you missed the overview and would like more information, please contact Amy Brower at abrower@acmg.net.

DON'T FORGET...

We would LOVE your feedback on the NBSTRN website! Go to www.NBSTRN.org and take our 3 minute survey, conveniently located on the homepage!



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.

February 16-17—Data Access Meeting, Washington, DC

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



VRDBS Update

Pilot states are working closely with NBSTRN and 5AM to map data elements to the VRDBS application and database including: conditions, race/ethnicity, feeding status, and other data fields required for each DBS specimen. Four states have provided test files and test import processes have been conducted and reviewed in preparation for initial data import into the VRDBS. State specific training will be provided as well as public training. Public training is available to anyone interested and you may register for any of the monthly webinars through the NBSTRN website: <http://nbstrn.org/research-tools/virtual-repository-of-dried-blood-spots/demo-dates>.



2012 VRDBS Online Training & Demos

We will be hosting one hour monthly training sessions which will cover a variety of topics and provide time after the demonstration for questions. Please visit our website to see a complete list of webinars. While each webinar is geared toward an intended audience, anyone is welcome to join the webinar to learn more about VRDBS.



Intended Audience	Date	Webinar Topic
Investigator	January 19, 2012, 2:00 PM ET Registration link: https://www1.gotomeeting.com/register/111649545	<ul style="list-style-type: none"> About the Virtual Repository How to Use This Site Research Support
State Administrator and State Lab Technician	February 16, 2012, 2:00 PM ET Registration link: https://www1.gotomeeting.com/register/863903768	<ul style="list-style-type: none"> About the Virtual Repository Responding to Questions Institution Administration Request Administration