

Where can you see us next?

ASHG Annual Meeting
October 11-15th ,
2011
Montreal, Canada

APHA Annual Meeting
October 29 –
November 2nd, 2011
Washington, DC

APHL NBS & Genetic
Testing Symposium
November 7-11th,
2011
San Diego, CA

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

CONTACT US!

**NBSTRN
Workgroup
Meetings....**

NBSTRN IT
Workgroup
October 20-21st ,
2011
Bethesda, MD

NBSTRN Bioethics
and Legal
Workgroup
November 2-4, 2011
Bethesda, MD

NBSTRN Standing
Committee
Workgroup Meeting
December 1-2, 2011

NBSTRN NEWSLETTER



NBSTRN
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

October 2011

Welcome

In our October Newsletter, the NBSTRN wanted to focus on partnerships and collaborations that we are currently involved with and the relationships we look forward to building. Hope you enjoy this issue as much as we enjoy putting it together.

Development of the Long Term Follow-Up (LTFU) Data Collection Tool

The Center for Biomedical Informatics (CBMi) at the Children's Hospital of Philadelphia (CHOP) and the NBSTRN have partnered to present a solution for collecting, managing, and delivering long-term care data for individuals identified with conditions through newborn screening. Effective capture of long-term clinical data for these individuals represents an exciting opportunity to establish a longitudinal data collective, which would produce a transformative resource for biomedical research. Delivery of a mechanism to collect, manage, and disseminate long-term clinical data in the context of newborn screening information and biomaterials is a key outcome for the remaining 2 years of the initial NBSTRN project period.

Using REDCap (**R**esearch **E**lectronic **D**ata **C**apture), this project will establish a network of centralized and institutionally-enabled infrastructure to support the capture and storage of longitudinal clinical data from individuals following newborn screening. REDCap is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. Data governance, security, and workflow processes will be developed and implemented to ensure that accrued data is standardized, secure, and of the highest possible quality for conducting research. These data will be made available to the research community using procedures that comply with established legislative and data practice guidelines. We plan to construct the NBSTRN data network as a highly scalable and extensible project that is compatible with other emerging national networks and data grids. We also plan to develop and contribute tools and procedures to the open-source community without restrictions to the greatest extent achievable.

Adaptation of the R4S Laboratory Performance Database

Through a subcontract with the Mayo Clinic, the NBSTRN is adapting the Region

4 Stork Laboratory Performance Database to collect information from the SCID and LSD Pilot Projects. So far, SCID data from 10 states has been entered into the database. LSD data (all non-newborn screening so far) has been entered from 8 states. Other than Krabbe screening in New York State, no LSD newborn screening has yet been implemented.

Visit our
updated
website [http://
www.nbstrn.org](http://www.nbstrn.org)

Collaboration

The NBSTRN believes that through collaboration and partnerships with various NBS groups and organizations information can reach a wider audience with a clear and concise message. In the past several months with the launch of our new website we have made a huge effort to link with other NBS organizations. We are excited to announce that the NBSTRN's latest partnerships with both Genetic Alliances **Babies First Test** and **Save Babies Through Screening Foundation** websites that were both launched the first



week of September. We plan on ensuring that duplication of efforts does not occur and look forward to linking to our new partners for Parent related information.



Save Babies Through Screening unveils new website and video. The video, "One Foot at a Time", is available in English and Spanish and can be viewed at <http://www.savebabies.org>



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VRDBS Update

Collaboration from our NBSTRN network is critical to the quality and usability of the VRDBS. As you may already know, several functional assessments have already been conducted in the past few months involving workgroup members and NIH investigators. In addition, feedback was elicited from selected workgroup members on the new Research Support functionality and suggestions and recommendations were incorporated into the VRDBS development stream. These collaborative efforts provided varied and unbiased user perspectives on the functionality of the VRDBS. As a result, the VRDBS is in the final stages of development in preparation for pilot. The pilot phase with states is targeted to start in the early part of next year. We appreciate and look forward to continued support and feedback from workgroup members and states as the VRDBS enters pilot phase.

As a reminder, enhancements to the VRDBS are released every other week and can be reviewed on the VRDBS demo site: <https://nbstrn-demo.5amsolutions.com/tissuelocator-web/browse.action>.

Bioethics & Legal Workgroup Update

The Bioethics & Legal Issues Workgroup, lead by Jeff Brosco and Edward Goldman, has been working hard to finish their current projects such as:

- NBS FAQs
- Updates on the VRDBS
- Content for NBSTRN.org website,
- User agreements for the VRDBS

This group has regular conference calls and is planning two additional meetings for this year to discuss ethical, legal, and social issues related to newborn screening. The first meeting was held in Salt Lake City, UT September 15-16th and focused on developing a national consensus on parental permission for pilot NBS research. The second meeting is planned for November 2-3, 2011 and will deal with unanticipated or incidental findings in newborn screening clinical services and research. We anticipate two white papers to be produced by the outcome of these two meetings.

The next face-to-face meeting for the Bioethics & Legal Issues Workgroup will be November 3-4, 2011.

We thank these workgroup members for the amazing work and are very excited to see the final products to their many work projects.