

Where can you see us next?

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

NBSTRN Standing  
Committee  
Workgroup Meeting  
December 1-2,  
2011

\*2012 NBSTRN  
Meeting calendar  
will be announced next issue!

# NBSTRN NEWSLETTER

November 2011



NBSTRN  
NEWBORN  
SCREENING  
TRANSLATIONAL  
RESEARCH  
NETWORK

## Welcome

In our November Newsletter, we provide an overview of the variety of resources that the NBSTRN has to offer, highlight our IT workgroup, share a brief update on the Virtual Repository of Dried Blood Spots, and highlight the upcoming NBSTRN meetings. As always feedback regarding the Newsletter is welcomed by all.

### **NBSTRN Resources:**

The NBSTRN is charged with developing an infrastructure that allows investigators access to robust resources for newborn screening research. These resources include but are not limited to information about state newborn screening programs and policies, newborn screening publications, disease specific registries or clinical databanks, funding opportunities, and networks of clinical centers and NBS laboratories interested in and willing to participate in newborn screening related research. Our website, [www.nbstrn.org](http://www.nbstrn.org), is the centralized web portal to all we have to offer. We are continuing our efforts to expand our resources on a daily basis, and will be showcasing them as they become available.

### State Profiles:

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 here in one, easy to access, resource. This information is in the process of being expanded to include scans of newborn screening dried blood cards and links to state-specific research-related resources.

### Disease Registries:

Patient registries, whether disease-based or product-focused, can provide your organization, as well as the health community, with invaluable data about the natural history of a disease under standard care practices and/or the safety and effectiveness of a product. These data can then be presented as evidence to:

- Meet safety requirements and manage benefits and risks
- Provide evidence to meet evolving coverage or reimbursement requirements
- Generate scientific evidence and publications
- Develop Treatment Guidelines
- Demonstrate good product stewardship

### Investigator FAQs:

Innovative translational research is necessary to improve the newborn screening process. This research must be conducted in an ethical manner that respects and protects the rights of children and their families. The Institutional Review Board (IRB) process is the mechanism by which oversight of this type of translational research is provided. These FAQs are intended to provide potential newborn screening researchers and IRB members with guidance regarding some of the ethical and regulatory issues that may arise concerning translational research to improve newborn screening, particularly with respect to the design of the research project.

## NBSTRN Presentations

The NBSTRN staff has made it a goal to present at scientific and organizational meetings to promote the NBSTRN. Just some of the meetings that we have been to in the last year include:

- \*International Congress of Human Genetics (ICHG)/ASHG
- \*American Public Health Association (APHA)
- \*APHL Genetics and Newborn Screening Conference
- \*American College of Medical Genetics Annual Meeting
- \*Association of Maternal & Child Health Programs (AMCHP)
- \*National Coalition for Health Professional Education in Genetics (NCHPEG) Annual Meeting
- \*Association of Medical Laboratory Immunologists (AMLI)
- \*The Annual World Congress – Lysosomal Disease Network
- \*Society of Inherited Metabolic Disease Annual Meeting
- \*NLM Health Informatics Meeting
- \*Genetic Alliance Annual Meeting

**Please let us know of any other meetings that the NBSTRN can attend and share the message and goals of the project!**

In early October, California Governor Jerry Brown signed into law March of Dimes-sponsored Assembly Bill 395, which will now permanently add Severe Combined Immunodeficiency (SCID) to the California Newborn Screening Panel.



## VRDBS Update

In our efforts to promote and utilize data standards, the NBSTRN has been working collaboratively with the National Library of Medicine (NLM). Recently, the VRDBS data model and DBS searching capabilities have been updated to align with NLM standard terminology for the Feeding Status data field. Specifically, the Feeding Status search criteria have been further expanded to provide even more flexibility to users filtering for Specific DBS specimens. We realize that many states do not collect this information in this detail at this time, but we are including it in the VRDBS for anticipation of future standardization among states. The following Feeding Status criteria are now available in the VRDBS for data imports from states and Specific DBS searching (each with possible values: YES, NO, Unknown, Not Reported):

- Breast Milk
- Lactose Formula
- Lactose-Free Formula
- TPN
- NPO
- IV Dextrose
- Carnitine
- MCT Oil

This enhancement to the Feeding Status can be viewed in the VRDBS demo site:

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

## IT Workgroup Update

This month we're highlighting the IT workgroup. This group has been focusing on FISMA compliance, LTFU data Collection tool, and assisting with various VRDBS issues. The IT workgroup just had their face-to-face meeting in Bethesda on October 20th and 21st. Goals for the meeting were:

1. Update the IT WG with respect to the recent changes made to the VRDBS and provide description of current status & emerging issues
2. Update the IT WG with respect to LTFU Uniform Data Set Efforts and Emerging issues
3. Inform the IT WG regarding the progress to date with FISMA for R4S, nbstrn.org, VRDBS, & LTFU.
4. Discuss impending NBSTRN changes due to FISMA Moderate for IT WG and Network of Experts
5. Update the IT WG with respect to LTFU project status & discussion of emerging issues
6. Update the IT WG with respect to FISMA-Moderate Planning for LTFU project & discussion of emerging issues

During the meeting, a new IT workgroup chair was announced. We are excited to introduce Marshall Summer, MD from the Children's National Medical Center. As always, all workgroup members are welcome to check out all of the different IT work products on the IT workgroup wiki page.