

Where can you see us next?

DMD Newborn Screening Symposium
September 11-12, 2012
Bethesda, MD

Public Health & Law Conference
October 10-12, 2012
Atlanta, GA

Annual Meeting of the American Society of Human Genetics (ASHG)
November 6-10, 2012
San Francisco, CA

PRIM&R Advancing Ethical Research Conference
December 4-6, 2012
San Diego, CA

NBSTRN Workgroup Meetings....

NBSTRN Laboratory Workgroup Meeting
September 27-28
Washington, DC

NBSTRN Bioethics and Legal Issues Workgroup Meeting
October 17-18
Washington, DC

NBSTRN Standing Committee Meeting
December 6-7
Washington, DC

NBSTRN NEWSLETTER

September 2012



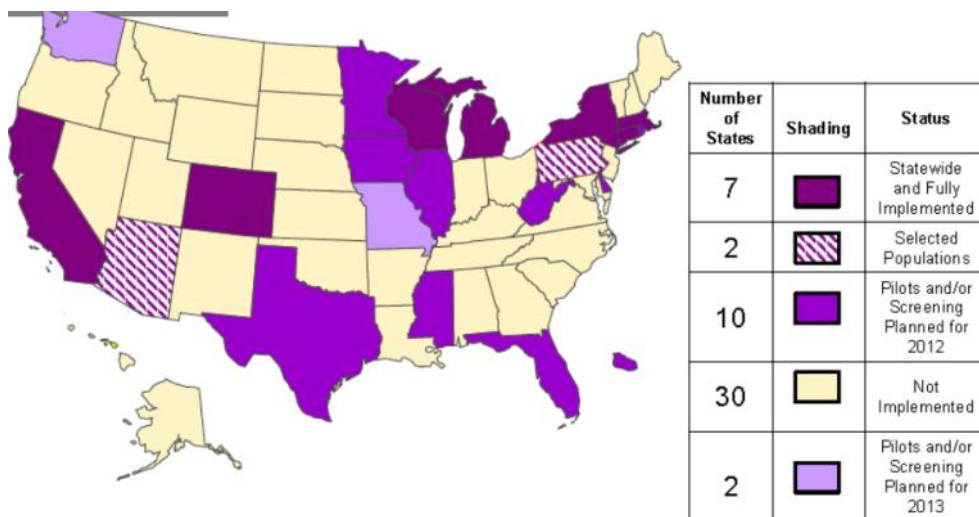
SCID National Monthly Calls

NBSTRN hosts and facilitates monthly calls of key stakeholders across the United States. The hour-long calls are held on the fourth Friday of each month and are led by Michele Caggana, PhD FACMG from the Wadsworth Center, New York Department of Health. A standing agenda focuses on the implementation of SCID newborn screening, new discoveries related to SCID newborn screening, diagnosis, and treatment, the education of family members and medical providers, and the identification of new hypothesis related to immune deficiencies.

Staff from the Centers for Disease Control (CDC) provide updates on quality assurance and proficiency programs each month. Staff from Mayo and NBSTRN curators, Fred Lorey, PhD and Roshini Abraham, PhD, provide updates and tutorials on the use of this analytical data collection and analysis tool each month and as requested by states, researchers and clinicians. NBSTRN collects and disseminates information from pilot and early adopter states to states that are not yet screening.

The monthly calls also facilitate the identification of implementation of issues, barriers to newborn screening adoption and track the status of SCID newborn screening across the United States. Key issues discussed this quarter include: (1) makeup of State advisory boards; (2) procedure for referral of screen positive cases e.g. whether referral to immunologists or infectious disease specialists; (3) technical troubleshooting and need for a forum to share technical information; (4) awareness of CDC efforts related to control materials and technology training; (5) nationwide tracking of screen positive cases; and (6) strategies to increase usage of R4S SCID module that tracks diagnosis and analytic characteristics.

A SCID Resource page was created on the NBSTRN website that includes protocols for screening, short-term and long-term follow-up, and educational brochures and links to the ACMG ACTION sheets. Educational brochures from several states and the Immune Deficiency Foundation (IDF) are included on the NBSTRN website for use by interested stakeholders. A map of the June implementation status in the United States is below.



VRDBS Goes Live!

The Virtual Repository of Dried Blood Spots (VRDBS) is opening September 26th! Look out for the ACMG, NICHD, and 5AM Solutions press releases and other various articles and informational ads. Throughout our marketing campaign the NBSTRN will stress that the VRDBS is a secure resource to access over **2 million de-identified DBS**, it facilitates communication between researchers and newborn screening programs, and provides key information about state programs.

The VRDBS is a secure web-based tool that presents information from participating states and provides a centralized, de-identified view of DBS, allowing researchers to locate and request specimens from participating states.

The VRDBS insures that states have complete autonomy over the DBS and maintains the privacy of those from whom the specimens came.

Note: Only approved investigators with research interests will be approved for participation in the VRDBS. Investigators are required to upload their CV/Biosketch, their professional affiliation and detailed information about their pending research.

Spread
the
Word!!!!



N B S T R N
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

VRDBS MONTHLY WEBINARS

With the opening of the VRDBS in September, the NBSTRN will be promoting our informational VRDBS monthly webinars to all that are interested in joining. Please go to for more information: <https://www.nbstrn.org/node/184>

Date	Webinar Topic
August 16th 2:00 PM ET	About the Virtual Repository How to Use This Site Research Support
September 20th 2:00 PM ET	Search for Dried Blood Spots Request Dried Blood Spots Provide feedback on Dried Blood Spots
October 18th 2:00 PM ET	About the Virtual Repository How to Use This Site Research Support
November 15th 2:00PM ET	Search for Dried Blood Spots Request Dried Blood Spots Provide feedback on Dried Blood Spots
December 20th 2:00PM ET	About the Virtual Repository How to Use This Site Research Support