

Where can
you see us
next?

2012 ACMG Annual
Clinical Genetics
Meeting
March 27-31, 2012
Charlotte, NC

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

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

NBSTRN Workgroup Meetings....

NBSTRN Labor-
atory
Workgroup
Meeting
March 1-2,
2012 Washing-
ton, DC

NBSTRN IT
Workgroup
Meeting
April 5-6, 2012
Boston, MA

NBSTRN NEWSLETTER



March 2012

Update on LTFU Data Resource: Validation of Data Capture Tool

The NBSTRN is developing a long-term follow-up data resource for newborn screening research and related efforts. This resource will be available for researchers to use to advance understanding of the natural history of conditions that are part of routine newborn screening as well as new conditions that are candidates for screening.

In addition to data sets and definitions, we are coordinating the development of a data capture tool and information management system. This development is being led by Dr. Pete White and his team at the Center for Biomedical Informatics (CBMi) at the Children's Hospital of Philadelphia. The CBMi team is actively creating electronic clinical report forms using the data sets and definitions as the starting point while working directly with grantees to refine question and answer lists.

An important part of the development process is to solicit feedback from clinicians and researchers who may use the tool in the future. This process of evaluating a software tool during the development helps to insure that the tool meets the needs of the user. The CBMi team recently completed the first validation of the data capture tool with Dr. Janet Thomas and Erica Wright at the Children's Hospital Colorado. The two day validation included role playing with the clinical report forms, extensive discussion of clinical practice workflow and observation of actual patients in the metabolic clinic. The Colorado team provided timely and important feedback that will shape the development of the tool and future validations. A big thank you to Dr. Thomas, Ms. Wright and their colleagues. Next up for the CBMi team is a visit with clinicians at their own institution.

"It was great to spend two days with Jeff and Stacey from CHOP, witnessing all of their hard work in translating the goals of the NBSTRN and applying these goals into a reality with the development of the RedCap long-term follow-up resource."

Erica Wright, MS CGC

Social Media

The NBSTRN is excited to announce our new social media accounts on Facebook and Twitter! Friend us and find out where we are, what we are doing and how we are trying to impact newborn screening. To date we have 21 "Likes" on Facebook and 32 Twitter Followers. We are excited to take on the challenge of reaching 1,000 likes and followers by the end of 2012. Help us reach our goal!



DON'T FORGET...

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



NBSTRN
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

The NBSTRN team attempts to attend as many newborn screening-related academic meeting as we can to spread the word about the Newborn Screening Translational Research Network. In addition to having presentations and exhibit booths at various meetings; the NBSTRN team would be happy to host short informational teleconferences for various organizations and groups to describe the NBSTRN, the Virtual Repository, or the LTFU Data Capture Tool. Please let us know if your organization may want to hear more about the NBSTRN either in person or via teleconference. We are excited to continue promoting our wonderful tools and resources.

VRDBS Pilot Starting!

The Virtual Repository of Dried Blood Spots (VRDBS) is gearing up for the launch of our pilot this spring. We've started holding public training webinars each month to introduce the key features of the system. Our first two sessions in January and February were well attended by investigators, clinicians, and state newborn screening program personnel. Our next session will be March 15th at 2:00 PM Eastern. You can learn more about future sessions or view the slides from previous sessions at <https://www.nbstrn.org/research-tools/virtual-repository-of-dried-blood-spots/demo-dates>.

For more information about the NBSTRN visit our website at <http://www.nbstrn.org> or contact Amy Hoffman at ahoffman@acmg.net.