

NBSTRN NEWSLETTER



N B S T R N
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

Where can you see us next?

AMCHP Meeting
February 9-12, 2013
Baltimore, MD

WORLD Symposium
February 12-15, 2013
Orlando, FL

2013 Joint Meeting of
the Newborn Screen-
ing and Genetic
Testing Symposium
and International
Society for Neonatal
Screening
May 5-6, 2013
Atlanta, GA



MARK YOUR CALENDARS!

NBSTRN Network
Meeting
April 8-9, 2013
Washington, DC

Registration
information will be
coming soon!

January 2013

NBSTRN Resources & Services: What Does NBSTRN Have for You?

The NBSTRN provides researchers with tools for successful collaboration in the newborn screening community.

NBSTRN is for any research related to newborn screening. This can include:

- ◆ New screening technologies
- ◆ Improvement of current screening technologies
- ◆ New therapies for conditions identified via NBS
- ◆ Screening of candidate conditions for NBS
- ◆ Long term follow-up (LTFU) of conditions identified via NBS

Whether you're a seasoned investigator or new to the research field, NBSTRN can help you navigate the grant process.

NBSTRN resources are free to access via www.NBSTRN.org:

- ◆ Letters of support for the grant writing process
- ◆ Study planning consultation
- ◆ Bioethical information related to NBS
- ◆ Access to DBS specimens
- ◆ Information to help you submit NIH grants in a timely fashion
- ◆ State specific IRB information
- ◆ Model consent form modules that you can tailor to your research
- ◆ Standardized LTFU data sets and electronic data collection tool
- ◆ Links to NBS-related websites

If you have topics for inclusion in future newsletters, please let us know by emailing ismotrich@acmg.net

Spotlight on NBS Researcher

As the new year begins, the NBSTRN would like to take this time to recognize and celebrate a person who has made a massive impact in the field of Newborn Screening. This person introduced the first newborn screening test in the United States for phenylketonuria (PKU) in the early '60s and the use of his method to collect the heel stick blood for newborn screening is now standard. This individual began his clinical career as a cancer research doctor but became interested in preventing mental retardation after his second son John was born with developmental disabilities and his niece was diagnosed with PKU.

Not sure who we are talking about yet? Go to: <https://www.nbstrn.org/Misc/Spotlight> to read more!

Workgroup Wiki Update

A couple of years back, the NBSTRN team gave workgroup members access to the NBSTRN wiki. We envisioned this being a place where workgroup members could share documents, ideas, and review materials posted by the NBSTRN staff. Over the last year, we noticed that fewer and fewer workgroup members utilized this tool. Therefore, the NBSTRN team has decided to **cancel** the NBSTRN wiki as of January 1st, 2013. We'll continue to connect with workgroup members via email.

Please let us know if you have any questions and/or comments.

VRDBS Update

Improvements on the VRDBS are continuous, the NBSTRN staff strives to ensure that regular updates and maintenance on the system are performed. However, we do like to come up with NEW and INNOVATIVE ways to help the NBS researcher. Whether it's with the State profiles or allowing researchers to contact the states directly, we strive to offer the best resources. Now that we are in the last year of the contract, we are looking for other ideas on how to improve the Virtual Repository. We believe that together with our federal partners and workgroup members, the VRDBS will continue to be a key tool in newborn screening research.

Email us with any suggestions and/or ideas!



NBSTRN
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK