

Where can  
you see us  
next?

Third National  
Conference on  
Genetics,  
Ethics, & the  
Law  
May 22-23,  
2013  
Charlottesville,  
VA

**MARK YOUR  
CALENDARS!**

NBSTRN Bioethics  
Workgroup Meeting  
June 6-7, 2013  
Bethesda, MD

NBSTRN Labs  
Workgroup Meeting  
June 27-28, 2013  
Bethesda, MD

# NBSTRN NEWSLETTER



N B S T R N  
NEWBORN  
SCREENING  
TRANSLATIONAL  
RESEARCH  
NETWORK

May 2013

## NBSTRN Network Meeting

We'd like to extend a warm "thank you" to all who participated in making this meeting a great success! We had a wonderful turn out for our Network Meeting on April 8-9th. Of the 117 people registered, 93 were able to join us.

We learned about the tools and resources available through the Newborn Screening Translational Research Network (NBSTRN), heard from grantees working with the NBSTRN, and discussed the implications of next generation sequencing on newborn screening. We also had presentations from other researchers working in NBS and learned about research opportunities throughout NIH.

Overall, it was a very productive day and a half and will help us to prepare for the next phase of the NBSTRN. We look forward in continuing our efforts in perfecting our tools and supporting newborn screening researchers.

In order to improve our efforts, we've developed a brief feedback survey. Please visit <http://surveys.acmg.net/redcap/surveys/?s=Eajw4H> to provide us your feedback on the Network Meeting.

To download the presentations, please visit <https://www.nbstrn.org/node/254>

## NBSTRN Network Meeting

April 8, 2013 8:30am - 5:00pm  
April 9, 2013 8:30am - noon

Hyatt Regency Bethesda  
Bethesda, MD



## Spotlight on NBS Researcher

The Spotlight of the month has received his PhD from the University of Tennessee in Biochemistry in 1972 and did post-doctoral training at the Oak Ridge National Laboratories. His areas of expertise are immunochemistry, dried-blood spot technologies, newborn screening for metabolic disorders, and laboratory quality assurance systems. He has been awarded more than 35 awards nationally and internationally, including the Robert Guthrie Award presented by the International Society for Neonatal Screening and the PHS Superior Service Award given by the US Department of Health and Human Services. His publications number well over 200, and he has contributed many book chapters, abstracts and presentations covering a variety of topics in public health. For more than 30 years, this researcher has led the way in developing and improving newborn screening methods, preventing death and disability for millions of children. Want to know more? Visit: <https://www.nbstrn.org/about/spotlight/Hannon>

## Newborn Screening Saves Babies...One Foot at a Time

Save Babies Through Screening Foundation, Inc. (SBTS) is the only national non profit newborn screening advocacy organization dedicated to improving the lives of children and their families by working to prevent disabilities and death resulting from disorders detectable through newborn screening. SBTS wants to see that every baby is screened effectively and comprehensively. Education of parents and health care providers is key to achieving this goal, and the educational videos produced by SBTS are critical to this effort.

The first video, "Newborn Screening Saves Babies...One Foot at a Time" has been circulated on DVD and Video to 48 states and over 65 countries worldwide, leading to increased awareness and understanding of newborn screening. The latest video, "Newborn Blood Spots Save Lives...One Spot at a Time" delves deeper into issues around newborn screening programs and test development, specifically about newborn blood spots left unused after comprehensive screening and how essential they are to maintaining quality and advancing state programs. Topics covered in the video include the importance of newborn screening in detection of rare treatable disorders, individual privacy and regulations that are in place to protect individuals if residual samples are used in quality assurance, new test development or research, IRB oversight of research using newborn blood spots, and an overview of state screening panels and policies.

If you have topics for inclusion in future newsletters, please let us know by emailing [ismotrich@acmg.net](mailto:ismotrich@acmg.net)



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