

# NBSTRN NEWSLETTER



N B S T R N  
NEWBORN  
SCREENING  
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Where can  
you see us  
next?

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 Standing  
Committee Meeting  
December 6-7  
Washington, DC

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### MARK YOUR CALENDARS!

NBSTRNetwork-  
ing Meeting April  
8-9, 2013

Washington, DC

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November 2012

## Providing Newborn Screening Specimens for Research: Legal Issues Faced by State Health Departments Webinar Series

The Providing Newborn Screening Specimens for Research webinar series is complete. However, due to the continued interest the entire webinar series is archived and now available on NBSTRN.org. Just as a reminder, this webinar series was about states that store and provide residual dried blood spots (DBS) for secondary uses, or are considering storage and secondary uses, may face an array of legal issues. This webinar series covered these legal issues – and related ethical issues – concerning secondary uses of DBS and associated data.

This webinar series was intended for public health attorneys, newborn screening programs and laboratories, institutional review boards, HIPAA privacy boards, privacy officers, researchers, and others who have interest in legal and ethical issues related to secondary uses of residual DBS.

Go to <https://www.nbstrn.org/node/186> to download the series!

## Save the Date!

With the new year right around the corner, we wanted to share our meeting dates. Please save the date!

Laboratory Workgroup Meeting — March 7-8, 2013

Clinical Centers Workgroup Meeting — April 4-5, 2013

\*\*Standing Committee Workgroup Meeting — April 7, 9, 2013\*\*

\*\*NBSTRNetwork Meeting — April 8-9, 2013\*\*

Bioethics and Legal Issues Workgroup — Meeting June 6-7, 2013

\*\*New dates from last newsletter\*\*

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

Happy Thanksgiving!



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## Congratulations Dr. Puck!

Congratulations to Dr. Jennifer Puck, who was recently named a new member of the Institute of Medicine. According to the IOM, election to the IOM is considered one of the highest honors in the fields of health and medicine and recognizes individuals who have demonstrated outstanding professional achievement and commitment to service.

The NBSTRN would like to congratulate Dr. Puck for this achievement and for her longstanding commitment to newborn screening.

The full announcement can be found here: [http://iom.edu/Global/News%20Announcements/2012-New-Members.aspx?utm\\_medium=email&utm\\_source=Institute%20of%20Medicine&utm\\_campaign=2012+New+Members&utm\\_content=IOM%20Newsletter&utm\\_term=Unknown](http://iom.edu/Global/News%20Announcements/2012-New-Members.aspx?utm_medium=email&utm_source=Institute%20of%20Medicine&utm_campaign=2012+New+Members&utm_content=IOM%20Newsletter&utm_term=Unknown)

## 2013 NBSTRN Networking Meeting

As a follow up to the NBSTRN Next Generation meeting which was held in 2009, the NBSTRN will be hosting the NBSTRN Networking meeting April 8-9th in the DC area. Current NBSTRN grantees will be invited to present on their projects, training will be provided on the various NBSTRN tools, and NBSTRN workgroups will meet to finish off current projects. In addition, we hope to have sessions driven by NIH Institute Project Officers on grant programs related to NBS research.

This meeting will be the perfect forum for NBSTRN updates and goals for the future as the 5 year contract comes to a close, September 2013. Please mark your calendars now so you can join us in 2013!

## VRDBS Update

The Virtual Repository of Dried Blood Spots has been live for over a month now! We were thrilled that over 200 media outlets picked up our press release, the VRDBS video has been a success on YouTube, and feedback has been extremely positive. The VRDBS now has eleven registered, vetted and approved investigators and our first request for specimens.

The NBSTRN staff is working diligently to market this amazing tool and are holding monthly demonstration webinars. These webinars show how simple and user friendly the VRDBS is. To join one of the upcoming webinars go to: <https://www.nbstrn.org/research-tools/virtual-repository-of-dried-blood-spots/demo-dates>