

Where can you see us next?

AMCHP Annual Conference
February 11-14, 2012
Washington, DC

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

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

Do you know of a good venue for a presentation from the NBSTRN?

CONTACT US!

NBSTRN
Workgroup
Meetings....
NEW!

*Data Access & Governance Meeting– February 16-17, 2012
Washington, DC

UPDATE!

NBSTRN Laboratory Workgroup Meeting,
March 1-2, 2012
is now in *Washington, DC!*

NBSTRN NEWSLETTER



NBSTRN
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

February 2012

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

DON'T FORGET...

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



NBSTRN Staff Update

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We would like to welcome to *NEWEST* member of the team, **Sophia Stich**. Sophie has just graduated from George Washington University with a Psychology degree and is joining the team as an Administrative Assistant. She can be reached at [sstich@acmg.net](mailto:ssstich@acmg.net).

VRDBS Update

In accordance with Health and Human Services final data collection standards for Race and Ethnicity as required by Section 4302 of the Affordable Care Act, the VRDBS database and data import process have been updated to accommodate for the data standards. For more information about these data standards see the HHS Press Release:

<http://www.hhs.gov/news/press/2011pres/10/20111031b.html>

2012 VRDBS Online Training & Demos

We are hosting one hour monthly training sessions which will cover a variety of topics and provide time after the demonstration for questions. Please visit our website to see a complete list of webinars. While each webinar is geared toward an intended audience, anyone is welcome to join the webinar to learn more about the VRDBS. You can also contact us for a private tour of the system.

We held our first webinar on January 19th and it was a huge success! We would like to thank all that participated and welcome any feedback you may have. We are very excited for our NEXT webinar which is geared towards the State NBS Programs.



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| Intended Audience | Date | Webinar Topic |
|--|---|---|
| State Administrator and State Lab Technician | February 16, 2012, 2:00 PM ET Registration link: https://www1.gotomeeting.com/register/863903768 | <ul style="list-style-type: none"> About the Virtual Repository Responding to Questions Institution Administration Request Administration |