

NBSTRN NEWSLETTER



N B S T R N
NEWBORN
SCREENING
TRANSLATIONAL
RESEARCH
NETWORK

Where can you see us next?

PRIM&R Advanc-
ing Ethical Re-
search Confer-
ence

December 4-6,
2012

San Diego, CA

2013 Joint Meet-
ing of the New-
born Screening
and Genetic
Testing Sympo-
sium and Inter-
national Society
for Neonatal
Screening

May 5-6, 2013
Atlanta, GA

NBSTRN Workgroup Meetings

Standing Com-
mittee Meeting

December 6-7

Bethesda, MD

MARK YOUR CALENDARS!

NBSTRNetwork
Meeting

April 8-9, 2013

Washington, DC

December 2012

NBSTRN Resources

The Newborn Screening Translational Research Network (NBSTRN) creates a centralized point of access to information valuable to conducting newborn screening research. We have many wonderful resources available on the NBSTRN.org site.

Disorders identified through newborn screening are typically rare and finding information about them requires accessing multiple information portals. In addition newborn screening related research requires knowledge about state regulations, IRB requirements, and consideration of multiple ethical and legal issues.

As a solution, the NBSTRN developed the resources listed below that facilitate access to residual dried blood spots, screening information, clinical history data, and state newborn screening programs.

- The Virtual Repository of Dried Blood Spots (VRDBS)
- Information about the rules, regulations, and requirements related to NBS and research (State Profiles)
- Guidance regarding some of the ethical and legal issues related to NBS research (Investigator FAQs)
- Long Term Follow Up (LTFU) Data Sets for conditions currently screened
- Data Collection Tool for LTFU
- Laboratory Performance Database (R4S)

Additionally, Links to patient registries and newborn screening related information can be found under the 'Related Links' section.

Visit us today for more information!

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

Happy Holidays from all the NBSTRN Staff!



Are you friends with us on Facebook?

The NBSTRN Facebook page, has the most up-to-date NBSTRN information. Constant meeting updates, webinar information and NBS news is readily available via our Facebook. With over 100 "Likes" and many more organizations, universities, and various government affiliates linked to our page; our Facebook page is a one stop shop for any and all NBS info!

In addition, the NBSTRN links to Twitter from our Facebook page. Become our Facebook friend and our Twitter follower by going to NBSTRN.org and clicking on the social media icons under the News and Updates section.

Marketing

One of our goals for the upcoming 2013 calendar year is to continue our marketing by attending Rare Disease meetings . The NBSTRN currently goes to many of the NBS meetings and will continue to do so. However, we are trying to widen our base and target certain researchers that we believe may attend various Rare Disease meetings.

If there are any additional meetings that you think the NBSTRN should go to, please email Irina Smotrich at ismotrich@acmg.net

VRDBS Update

The Virtual Repository of Dried Blood Spots (VRDBS) has been live for two months now and we are happy to report that 15+ registrations were received and approved, one request has been submitted! Additionally, our monthly training webinars have been well attended. We intended to continue our marketing campaign and hope that registration keeps climbing steadily.

The VRDBS is one of many wonderful resources the NBSTRN has to offer, visit www.NBSTRN.org for more information!

