

Mark your calendars!

ASHG Annual Meeting

Oct 6-10, Baltimore,
MD

NORD Rare Summit

Oct 21-22, Arlington,
VA

APHL NBS and Genetic
Testing Symposium

Feb 29– Mar 3, St.
Louis, MO

NBSTRN NEWSLETTER

OHRP releases webinars on Notice of Proposed Rule Making regarding the Common Rule

On September 8th, 2015, a Notice of Proposed Rule Making (NPRM) was published in the Federal Registrar. The U.S. Department of Health and Human Services (HHS) and fifteen other Federal Departments and Agencies announced proposed revisions to modernize, strengthen, and make more effective the Federal Policy for Protection of Human Subjects that was promulgated as a Common Rule in 1991.

The Office for Human Research Protections (OHRP) has developed six short webinars covering the main topics of the NPRM to help the public understand the proposals.

6 Topics Covered:

Overview of the NPRM—34 minutes, Jerry Menikoff, Director, OHRP

Exclusions and Exemptions—30 minutes, Jerry Menikoff, Director, OHRP

Informed Consent—28 minutes, Jerry Menikoff, Director, OHRP

IRB Review and Operations—18 minutes, Julia Gorey, Policy Analyst,

Research with Biospecimens—22 minutes, Julie Kaneshiro, Deputy Director, OHRP

Secondary Research Use of Data—21 minutes, Ivor Pritchard, Senior Advisor to the Director, OHRP

To watch now, go to: <http://www.hhs.gov/ohrp/education/training/nprmwebinars.html>

Please send any questions or comments about the webinars to OHRP-Edu@hhs.gov.

To submit comments on the NPRM, please follow the instructions provided on the OHRP webpage entitled “NPRM for Revisions to the Common Rule” that is also accessible from the OHRP homepage.





Spotlight on a Newborn Screening Researcher

October's spotlight researcher is a professor of pediatrics, as well as community and family medicine at Duke University School of Medicine. At Duke University, he supervises residents in the provision of well-child and acute care. He also coordinates research activities that ensure the quality of care received by children and their families.

This mystery researcher has an extensive background in epidemiology and biomedical engineering. His research focuses on improving the quality of care that children receive by strengthening the linkages between primary care, specialty care, and public health services. He studies a full array of conditions that address these research focuses. Recently, he did work on evaluating health care delivery for children with congenital hypothyroidism, and assessed the evidence base around screening for Krabbe disease, and evaluated the quality of vision screening services delivered in the primary care setting.

Read more and find out who the Researcher of the Month is by visiting:

<https://www.nbstrn.org/about/spotlight-researchers>

Steering Committee Meeting Update

The NBSTRN Steering Committee met immediately following the NBSTRN Network Meeting on the afternoon of September 11th. This meeting was structured around the deliverables listed in the NBSTRN Statement of Work (SOW) with NBSTRN staff presenting year 2 accomplishments to the committee and presenting the goals for year 3 for the NBSTRN contract. The Steering Committee also reviewed the progress that has been made on its recommendations for the NBSTRN from the Spring 2015 meeting alongside the SOW. The NBSTRN fully debriefed the committee on its ongoing maintenance of existing tools as well as its development and implementation process for its new ELSI tools. The effects of H.R. 1281 and the Notice of Proposed Rule Making (NPRM) were discussed in length. The committee will meet again in person next Spring.

If you have topics for inclusion in future newsletters, please let us know by emailing

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