



NBSTRN NEWSLETTER

Where will you see us
next?

Region 4 Midwest
Genetics Collaborative
Regional Meeting
April 29-May 1, 2014
Lansing, MI

Parental Permissions for Pilot Newborn Screening Research

On January 6, 2014, the Official Journal of the American Academy of Pediatrics published "*Parental Permissions for Pilot Newborn Screening Research: Guidelines From the NBSTRN*".

This paper addresses a significant problem in pilot studies: how to engage parents in the permissions process within population-based research. The paper presents an ethical and legal analysis of the role of parental permissions in pilot studies of newborn screening tests or conditions.

If you are a researcher who is interested in this issue and you would like to learn more, please visit the [NBSTRN Publications](#) section of [NBSTRN.org](#).

To learn more about pilot studies that have used the NBSTRN as a resource to facilitate research, visit the [Research Projects](#) section of [NBSTRN.org](#).



SPECIAL ARTICLE

Parental Permission for Pilot Newborn Screening Research: Guidelines From the NBSTRN

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abstract

NIH

There is broad recognition of the need for population-based research to assess the safety and efficacy of newborn screening (NBS) for conditions that are not on current panels. However, prospective population-based research poses significant ethical, regulatory, and logistical challenges. In the context of NBS, there have been a variety of approaches that address parental decision-making in pilot studies of new screening tests or conditions. This article presents an ethical and legal analysis of the role of parental permission by the Bioethics and Legal Work Group of the Newborn Screening Translational Research Network created under a contract from the National Institute of Child Health and Human Development to the American College of Medical Genetics and Genomics. Circumstances are outlined in which a waiver of documentation of permission or a waiver of permission may be ethically and legally appropriate in the NBS context. These guidelines do not constitute American Academy of Pediatrics policy. *Pediatrics* 2014;133:1-8



Spotlight on a Newborn Screening Researcher

This Spotlight Researcher received degrees in English and History from Stanford University and then went on to earn her JD from Vanderbilt University School of Law in 1992. After being introduced to issues in health care while working on Capitol Hill, this researcher went on to study medicine and received her MD from Tulane University. She completed her residency in Pediatrics and is currently focusing on ethical issues in newborn screening, such as how the state maintains the integrity of its newborns screening program.

Our researcher is a remarkable advocate for Newborn Screening and her recent research publications focus on investigating the impact of the Michigan Department of Community Health's policy requiring parental consent for research use of residual dried blood samples (DBS).

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

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



NBSTRN Parents

The Parents' section of the NBSTRN website has been updated as part of the website redesign effort undertaken this winter. Even though the main audiences of the NBSTRN project are researchers and members of the newborn screening community, the Parents' section is an important part of the website because it is an opportunity for the NBSTRN team to highlight the positives of newborn screening research and highlight the resources that are available to parents through our partners.

The Parents' section of the website is divided into three parts so that parents can easily navigate answers to their questions. The first part addresses the basic question of 'what is newborn screening?' and broadly describes the process. The second section is tailored toward questions about the utility of newborn screening research, in an effort to succinctly describe the context in which newborn screening research occurs. The last section is a brief description of where parents can get more information about newborn screening and research affiliated with it. Find out more by visiting the [For Parents](#) page on [NBSTRN.org](https://www.nbstrn.org).



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Newborn Screening
Translational Research
Network

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