

## Abstract 37

### **PARENTAL DECISIONS FOR ACCEPTING OR DECLINING NEWBORN SCREENING FOR FRAGILE X: ANTHROPOLOGICAL PERSPECTIVES ON GENETIC RESPONSIBILITY**

Debra Skinner<sup>1</sup>, Summer Choudhury<sup>2</sup>  
University of North Carolina at Chapel Hill, USA<sup>1</sup>  
Eastern Carolina University, Greenville, NC, USA<sup>2</sup>

Fragile X syndrome is an excellent prototype for studying issues that will arise in an era of greatly expanded newborn screening. These issues include the willingness of families to have their newborns screened for both premutation and full mutation fragile X, families' reasons for accepting or declining screening, and the context of the consent process as this may influence families' decisions. As part of the Fragile X Newborn Screening Study being conducted at the University of North Carolina Hospitals, we are conducting research on these issues. This presentation summarizes the extent to which families from diverse sociocultural groups consent to newborn screening for fragile X, the reasons they decline or accept screening, and family or socio-cultural factors related to screening decisions. Results from a brief survey, a content analysis of open-ended responses, and an ethnographic study of the context of informed consent provide data on these questions for approximately 1,200 families who were offered newborn screening for fragile X within 24 hours of the baby's birth. Findings indicate the ways in which families understand the risks and benefits of screening, their sense of "genetic responsibility," and other beliefs and values that determine whether or not they chose to participate in the study. These findings provide insights into what information families need to make informed decisions about newborn screening for fragile X and the considerations researchers should take into account in future studies.

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