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Researchers Look for Ways Around Parent Consent Law

Last December, the Newborn Screening Saves Lives Reauthorization Act was signed into law with our parent consent requirements. Parents must now be asked before their baby’s DNA can be used for federally-funded research. Researchers and government agencies are feeling the impact. For example, a virtual repository of Baby DNA from four states will no longer share information with researchers.

Some hope the word “research” can be re-defined by giving research activities different names such as “public health functions” or “testing a new technology.” The Office for Human Research Protections is drafting guidelines and will define what qualifies as research. Then the public can comment. Be prepared to act when we ask you to do so.