

# How Does the BioTrust Protect Your Privacy?

*There are many levels of security at the Michigan Neonatal Biobank where blood spots are stored. Blood spots are stored using a code and not a person's name. Details that could pinpoint a child or family are removed. The Department of Health and Human Services (MDHHS) has been granted the highest level of protection, a Certificate of Confidentiality from the United States Department of Health and Human Services.*

Blood spots are separated from the newborn screening card and labeled with a storage code, then sent to the Michigan Neonatal Biobank for storage.



**1**

After newborn screening is completed, the filter paper containing left-over blood spots is separated from the newborn screening card that has the baby's directly identifiable information. A code is assigned to the remaining blood spots before transfer to the Michigan Neonatal Biobank for storage. The Michigan Neonatal Biobank can not access and does not receive any directly identifiable information.

Requests for blood spots and data must be approved by MDHHS Institutional Review Board, BioTrust Scientific Advisory Board and MDHHS Programs.



**2**

Research requests are reviewed and approved by the MDHHS Institutional Review Board and Scientific Advisory Board to ensure protection of human subjects. Both boards must approve a study before blood spots are released. All research requests must comply with BioTrust policies that have been developed with feedback from our Community Values Advisory Board. If a research study requires samples meeting certain criteria or asks for accompanying data, the MDHHS Program housing the data must approve its release. MDHHS will then conduct database linkages to select the right blood spots while still keeping blood spots and data confidential and coded.

Michigan Neonatal Biobank replaces storage code with a research code. Blood spots labeled with the research code given to researcher.



**3**

Once MDHHS identifies the blood spots and potential data required for an approved study, the Biobank receives a list of storage codes to retrieve blood spots for the study. Before the blood spots and potential coded data are released to a researcher the Biobank assigns another, different code. Thus, the code a researcher sees is two steps removed from the original newborn screening card number.

***Researchers requesting identified blood spots or data must get consent from subjects for use in the specific study.***