



New BioTrust Consent Form and Brochure!

Please review the updated consent material for new parents and contact the BioTrust Coordinator if you have any questions!



Revised BioTrust Consent Brochure: This brochure must be ordered separately from the newborn screening card ('kit'). Please order one BioTrust brochure for each newborn screening card. *Please read this revised brochure before distributing it to parents.*

Before parents makes a consent decision:

- Provide BioTrust consent brochure.
- Ask parent to read.
- Answer any questions.
- If a parent has more questions, contact BioTrust Coordinator.

Revised BioTrust Consent Form: Found in the back of the newborn screening card.

After parent reads BioTrust consent brochure:

- Ask parent to mark their decision.
 - Mark the "yes" box for consent
 - Mark the "no" box for decline
- Collect parent signature.
- Return white copy to state lab.
- Give pink copy to parent.

Before signing this form please read, *Your Baby's Blood Spots*. It gives details on how small drops of blood (blood spots) collected for newborn screening may be used in research through the Michigan BioTrust for Health. If you have questions, please call the Michigan Department of Health and Human Services (MDHHS) toll free at 1-866-673-9939.

Yes, my baby's leftover newborn screening blood spots *may* be used for health research.
By checking this box you understand:

- After newborn screening, blood spots are coded only with a number and stored up to 100 years at a secure site (Biobank). MDHHS can link the coded blood spots to your baby. This allows use of specific spots for research. It also allows MDHHS to find the right spots if you, or your grown child, change your mind.
- Researchers only receive coded blood spots. Details that could identify you, or your baby, are not provided.
- The risk of using blood spots in research is that your baby could still be identified. This risk is very low because many steps are taken to protect privacy.
- Research using blood spots must be approved by MDHHS. Blood spots can only be used for studies to better understand disease or improve the public's health such as research on cancer, birth defects and diabetes.
- Many laboratory methods are used to study biological or environmental factors such as genes, infectious agents, toxins and metals.
- Blood spot research may not directly help you, your child or your family. This type of research aims to improve the health of communities.
- Participation is voluntary. You can call MDHHS at any time if you change your mind. There is no penalty or loss of benefits for saying no or changing your mind.

No, my baby's leftover newborn screening blood spots *may not* be used for health research.
By checking this box you understand:

- Blood spots will be stored for up to 100 years but not used for research. The blood spots are stored so that the state lab can perform quality control tests and improve newborn screening.
- You must contact MDHHS if you do not want blood spots stored for any reason after newborn screening.

Parent Signature _____ Date _____
Your choice applies to all blood spots collected for newborn screening. Please visit www.michigan.gov/biotrust for further information. For questions about your research rights or whom to contact in case of a research-related injury, please call the MDHHS IRB at 517-241-1928.

MDHHS Copy

BioTrust Coordinator: 1-866-673-9939 or biotrust@michigan.gov
Newborn Screening Ordering: www.michigan.gov/nbsorders or 1-866-673-9939