

BIOTRUST ALTERNATE PARENTAL CONSENT – NEWBORN SCREENING BLOOD SPOT RESEARCH USE

Michigan Department of Health and Human Services

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| Child's Name at Birth | Date of Birth |
| Newborn Screening Kit Number | Check Birth Order if Multiple Births <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 |
| Mother's Name at Time of Child's Birth | Hospital of Birth |

Before you sign this form please read, Your Baby's Blood Spots (MDHHS-Pub-1216). It explains in more detail how your baby's blood spots may be used in health research through the Michigan BioTrust for Health. If you still have questions, please call Michigan Department of Health and Human Services (MDHHS) toll free at 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.

Your choice applies to all blood spots collected for newborn screening. Please visit www.michigan.gov/biotrust for further information including research updates. 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.

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|------------------|------|
| Parent Signature | Date |
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Return document(s) via email, biotrust@michigan.gov, fax 517-335-9419, or mail:

BioTrust Coordinator, Newborn Screening (NBS) Follow-up Program, PO Box 30195, Lansing, MI 48909

The Michigan Department of Health and Human Services (MDHHS) does not discriminate against any individual or group because of race, religion, age, national origin, color, height, weight, marital status, genetic information, sex, sexual orientation, gender identity or expression, political beliefs or disability.

AUTHORITY: Michigan Public Health Code, Act 368 or 1978 **COMPLETION:** Voluntary