

## BIOTRUST FREQUENTLY ASKED QUESTIONS

### What are blood spots?

Soon after birth a few drops of blood are taken from a newborn's heel. The drops fill five or six spots on a filter paper card. These "blood spots" are used for newborn screening. Newborn screening ensures babies with rare diseases such as phenylketonuria (PKU), cystic fibrosis and sickle cell disease are found early for treatment. To learn more about newborn screening please visit [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening).



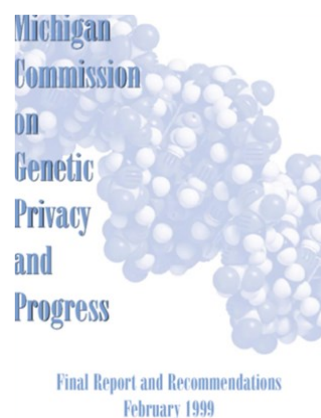
#### What do I need to know about blood spots?

All of the blood spots are not always needed. Five or six blood spots are collected to ensure there is enough for all of the newborn screening tests. If there is a positive (abnormal) test, the lab has enough spots to double check the result. This limits the number of newborns who need to have their blood drawn again and helps to ensure a disorder is treated as soon as possible. Once newborn screening is done, any unused parts and whole blood spots are stored indefinitely (forever). One unused spot is kept by the state public health lab for use by a parent or person (>18y), if needed. The rest of the blood spots are stored at a secure site called the Michigan Neonatal Biobank ([www.mnbb.org](http://www.mnbb.org)).

#### How long have Michigan blood spots been stored?

Blood spots dating back to July 1984 are being stored. Any blood spots received by the state lab on infants born before July 1984 have been destroyed.

#### Why have blood spots been stored?



Good lab practice requires that blood spots be kept for a length of time after newborn screening is done. The state lab has always stored blood spots after newborn screening, but the length of time has changed over the years. In the 1970s, blood spots were stored for 7 years and then destroyed. In the 1980s, the State of Michigan received legal advice to store blood spots until a child reached 21.5 years. In 1999, a Governor's task force called the Michigan Commission on Genetic Privacy and Progress recommended storing leftover blood spots indefinitely (forever) because of their value for future research. State law allows the Department of Health and Human Services to set the period of time for storage. In 2008, the policy was changed to save blood spots indefinitely.

#### *Important Reasons to Store Blood Spots*

- Blood spots are used to ensure quality newborn screening.
- Blood spots are also stored because they may be helpful to the baby's family in the future.
- Blood spots may also help researchers better understand diseases or find ways to improve health.

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### How have stored blood spots been used?

The state lab used blood spots to add newborn screening for cystic fibrosis in 2007 and for SCID (Severe Combined Immunodeficiency) in 2011.

The state lab used blood spots to protect the public's health by studying the spread of infectious diseases or public health epidemics. Anonymous samples were used in the 1990s to find out how many newborns were exposed to HIV.

Researchers used blood spots to look for better ways to diagnose leukemia and to test for mercury levels to find out if pregnant mothers were eating safe amounts of fish.

Parents have asked that their own child's blood spot be sent to researchers for studies; and to help diagnose a disorder or find reasons for a child's untimely death.



### Why use left-over blood spots for research?

Blood spots contain genetic and other kinds of biomarkers that may be useful for studying birth defects or chronic diseases. Blood spots may also show if there was exposure to infections or toxins (such as pesticides or lead) before birth. Blood spots are no longer needed after newborn screening is done. Because many blood spots can be provided at one time, it is easier for researchers to study very large numbers of people from all over the state. This is simpler than trying to collect a new sample from each person and may help speed up the chance of new discoveries, improve quality, and possibly reduce the cost of research. For more details about the research done using Michigan's stored blood spots please visit the "Research" page on the BioTrust website ([www.michigan.gov/biotrust](http://www.michigan.gov/biotrust)).

### Are Michigan's blood spots used for cloning or stem cell research?

No. Blood spots cannot be used for cloning. Michigan law also prohibits human cloning for any purpose and prohibits the use of state funds for human cloning. Therefore, blood spots cannot be used for cloning. Stem cells are specialized cells that currently can only be isolated from certain types of tissues which do not include left-over blood spots from newborn screening. Thus, Michigan's blood spots are not stored for stem cell research.

### What has been done with my child's (or my own) blood spots?

It is not possible to tell exactly which blood spots were used in the past for medical or public health research because all directly identifiable information was removed. New steps are now in place so the Department of Health and Human Services can track the blood spots but still maintain privacy and confidentiality. For more details please read the "*How Is Privacy Protected?*" FAQ page.

It is unlikely that all of your stored blood spots in the biobank will be used in research even if selected for one or more research studies. The choice to continue to allow research use of your child's (or your own) blood spots is yours to make. Please learn more and visit the "*Consent Options*" page on the BioTrust website ([www.michigan.gov/biotrust](http://www.michigan.gov/biotrust)).