

BIOTRUST FREQUENTLY ASKED QUESTIONS

What Is The Michigan BioTrust for Health?

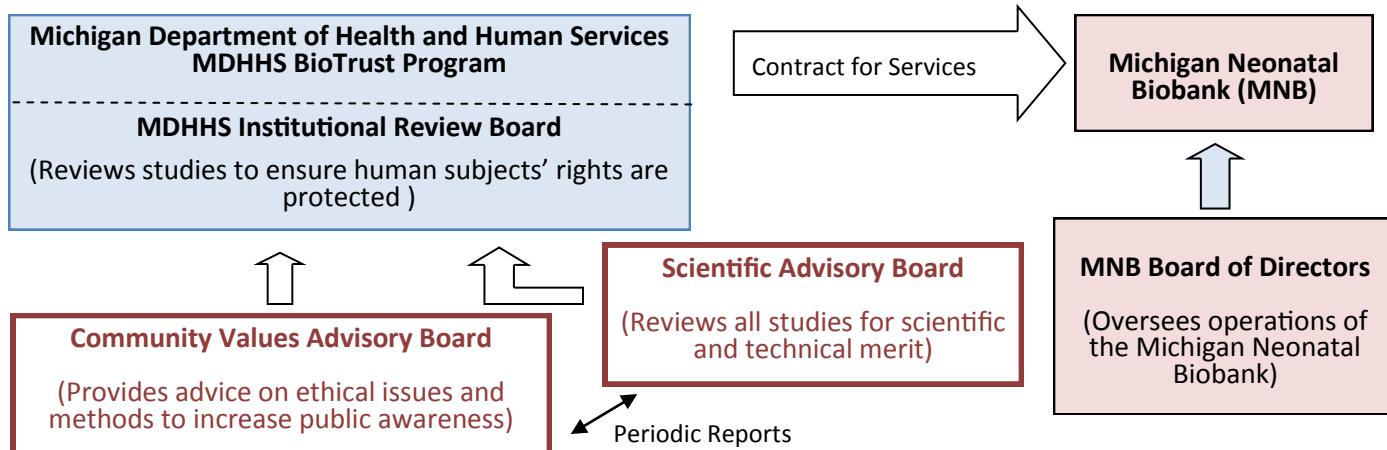
The **BioTrust** is a program run by the Department of Health and Human Services (MDHHS) to oversee the storage and use of Michigan's blood spots that remain after newborn screening is completed. Program components include outreach and community engagement, policy development, blood spot storage and coordination of research.

Who is in charge of the BioTrust?

MDHHS is responsible for the blood spot samples, holding them “in trust” for future research. The Michigan Neonatal Biobank (www.mnbb.org), a 501c3 non-profit charitable organization, is responsible for storage and day-to-day management of the blood spots.

Who helps MDHHS guide the BioTrust?

Four different advisory or review boards help guide BioTrust policies and operations. Board members represent the major state universities, research institutions, disease and advocacy organizations, community groups and the public.



What are the goals of the BioTrust?

The primary goals are to: (1) make blood spots more useful for medical and public health research while protecting privacy, (2) store blood spots to better preserve the samples, (3) encourage research, (4) engage and inform the public and (5) allow personal decision-making.

What kind of research does the BioTrust allow?

The only studies allowed are for medical and public health research. Guiding principles were developed with input from the Community Values Advisory Board. For more details and a list of studies using Michigan blood spots, please visit the “Research” page on the BioTrust website (www.michigan.gov/biotrust).

Do law enforcement officials or insurance companies have access to the BioTrust?

No. The BioTrust has been designated a medical research project by the MDHHS Chief Medical Executive. Under state law, the samples, data and other information included as part of this medical research project are protected and are not subject to forced disclosure to third parties.