

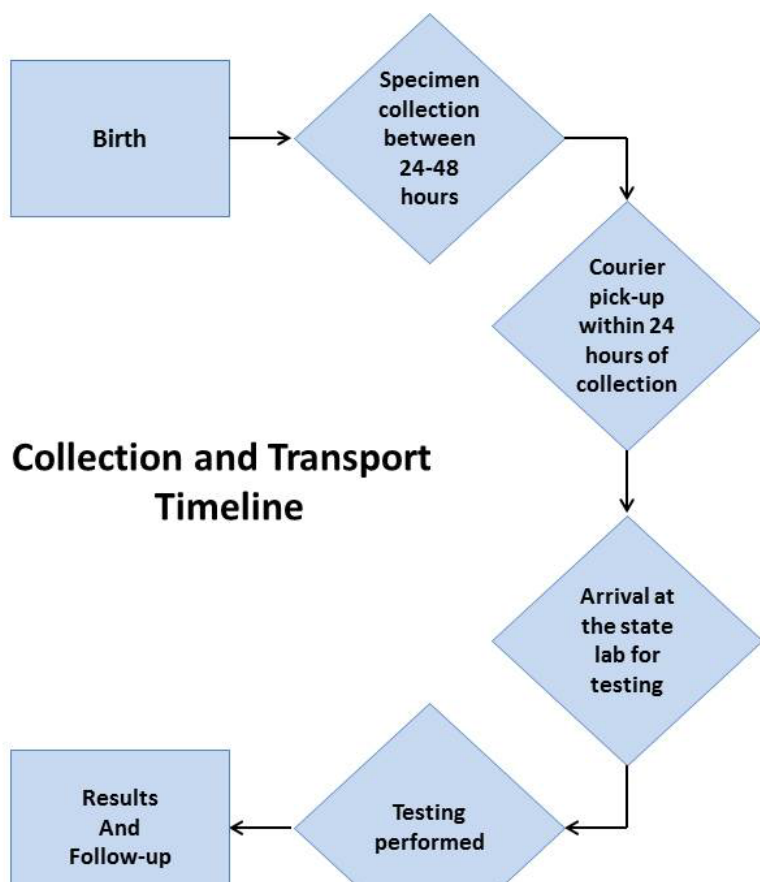
The Importance of Timeliness in Newborn Screening

About one in every 800 babies is born with a potentially severe or deadly condition that can be treated and managed if the child is properly diagnosed. These babies usually seem healthy at birth but can become extremely sick within days. The goal of newborn screening is to detect disorders quickly to provide early treatment. This can make the difference between a child leading a relatively normal life or having more significant developmental delays; long-term health care needs, or even death.

All infants born in Tennessee must have a newborn screening specimen submitted to be screened for certain genetic conditions. If tests are abnormal, the Department of Health follows up with the baby's doctor to initiate re-testing, confirmation and treatment from a specialist if necessary. Additionally, there is a national initiative to improve timeliness in newborn screening that sets recommendations for ensuring that all results be reported efficiently.

Aiden Cooper's Story

- Seemed healthy at birth
- Newborn screen collected at 2 days old
- Unable to keep down formula
- Discharged at 4 days
- Continued spitting up and losing weight
- Rash and enlarged stomach noticed at 2 weeks; due to enlarged liver and spleen
- Teams of doctors tried to figure out why Aiden was so sick for two weeks
- Nurse calls and tells the mother and informs her that Aiden's newborn screening form had been lost, but was located
- Sample tested 24 days after birth
- Test results are abnormal
- Diagnostic tests revealed that Aiden has Galactosemia**
- Treated, but suffers developmental delays caused by delayed intervention



**Galactosemia is a treatable disorder that prevents digestion of the sugar in breast milk and formula. Those affected cannot process galactose, a sugar in milk, so toxins build up in their cells as they drink breast milk or traditional formula. Undiagnosed, babies can develop serious infections, kidney and liver problems that lead to brain damage, organ failure, and potential death.

Story can be found via [The Milwaukee Journal Sentinel](#).

State Transit Time Reports

Quality Assurance Reporting

Tennessee State Law (TCA 68-5-401) requires that all infants born in the State of Tennessee receive screening for certain conditions using a dried blood spot (DBS) screen, for critical congenital heart disease (CCHD) using pulse oximetry and for congenital hearing loss via hearing screening.

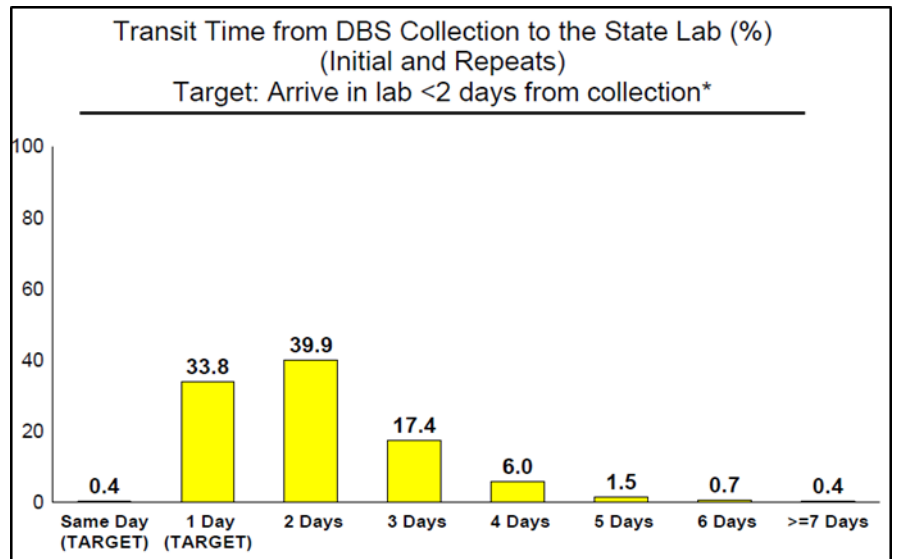
The Tennessee Newborn Screening Program has prepared the Monthly Quality Assurance Report to help show each facility's compliance with the law. The report also shows the number of unsatisfactory specimens submitted to the lab, the percent of specimens collected within 24-48 hours of birth and transit times, which is the time between the collection of the specimen and receipt in the State laboratory for testing. The report is intended to assist each hospital and the state in meeting the quality indicators of ensuring all infants born in Tennessee are screened in a timely manner.

Additional information in the report is meant to allow for the identification of possible process improvements at facilities to improve overall timeliness of newborn screening.

Help Continue Improvement

- Ensure that all specimens are picked up AND delivered on time
- Notify Hospitals and lab of

State Report May 2016



2014-2016 Transit Times to State Lab

