

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

October 13, 2021

Re: Changes in State Statutes and Other News

Dear Partners in Newborn Screening,

You may be aware that the Senate and House of Representatives of the Connecticut General Assembly enacted changes to Section 19a-55 (Newborn Infant Health Screening) of the general statutes that are effective October 1, 2021. Below is a summary of changes that will affect collectors and submitters of newborn screening bloodspot specimens.

- The statute now requires institutions and **midwives** caring for newborns, including licensed nurse-midwives and unlicensed midwives to collect a bloodspot sample within 24-48 hours after birth, unless a situation exists to warrant an early collection of the specimen or if collection of the specimen is medically contraindicated. It also requires facilities and midwives to submit the bloodspot sample to the state laboratory within 24 hours of collection. The Connecticut Newborn Screening Program (CT NBS) screens for over 60 disorders through bloodspot screening. The timely collection of the Newborn Screening (NBS) bloodspot specimen is crucial. Failure to submit the NBS bloodspot specimen in a timely fashion can lead to delays in the identification and treatment of a disorder. Bloodspot specimens collected after 48 hours of age may not allow enough time for results to be interpreted and reported before serious symptoms and in some cases, death, occur. These changes are in accord with the recommendations of US Department of Health and Human Services (USDHHS) Advisory Committee for Heritable Disorders in Newborns and Children (ACHDNC) for timeliness in newborn screening.
- The institution, nurse-midwife or midwife shall notify CT NBS when a specimen is not collected within forty-eight hours after the birth of the infant
 - because of infant's medical fragility
 - refusal by the parents when NBS conflicts with their religious tenets and practice
 - the newborn infant receiving comfort measures only
 - any other reason

Facilities and midwives who have access to the CT NBS Program's Maven System will document the reason that a heel-stick specimen was not collected by 48 hours in the "Laboratory" section of Maven and send a copy of a waiver form when applicable, by email (dph.nbstracking@ct.gov) or fax (860.730.8385) to the CT NBS Program. For those without access to Maven, written notification, including a signed waver and homebirth form where applicable, must be sent to the CT NBS Program by email (dph.nbstracking@ct.gov) or fax (860.730.8385) not later than 72 hours after birth. The homebirth notification form is to be completed by the midwife and



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submitted to the CT NBS Program for all infants born at home, including those cases where the parent has refused NBS. This notification is separate from the form that is submitted to vital records for the birth registry and should be completed and submitted by a midwife and not by a parent. It is recommended that midwives maintain copies of all samples and all forms submitted.

Please see the attached document for the complete text of Section 19a-55 (Newborn Infant Health Screening). Please note that deleted language is indicated by brackets and new language is underlined in the attached document.

Shipping recommendations

The CT NBS Program highly recommends that all samples are shipped with same or next day tracked delivery by courier to:

CT Newborn Screening Program
State Public Health Laboratory
395 West Street
Rocky Hill, CT 06067

Samples can also be personally dropped off at this address. A security guard is available to accept samples 24 hours per day, 7 days a week including holidays and weekends. When dropping off samples after regular business hours, please ring the bell at the guardhouse for admittance.

At this time, due to US Postal Service delivery delays, we are not recommending that samples be placed in the mail. However, if you choose to do so, please send samples with next day delivery and tracking to:

CT Newborn Screening Program
State Public Health Laboratory
PO box 1689
Hartford, CT 06144-1689

Quality Assurance Reports

In order to assist birthing facilities and midwives with monitoring their own performance in the area of specimen collection and shipping and other select quality indicators the CT NBS Program has created a report that will be sent quarterly to submitters of samples. It is anticipated that the initial report will be sent to submitters of samples in early November 2021.

CT NBS asks that every birthing facility to submit the name and email address of at least two individuals to receive this report to dph.nbstracking@ct.gov not later than October 15, 2021. It is recommended that one of these individuals be a representative of the facility's Quality Assurance department.

Updates to Maven

Please watch for an announcement in the upcoming weeks regarding changes to Maven that will affect how facilities print barcode labels and enter other information.

Redesigned webpages to be launched

Please watch for the launch of our redesigned CT NBS Program web pages later this month. The new site incorporates Health Care Provider and parent Specific information and features such as, an ask a question portal, educational videos, Newborn Screening news, on-line supply ordering and more!

Newborn Screening Education

The CT Newborn Screening Program is close to completing the pilot testing of our Digital Course: CT Newborn Bloodspot Screening Course for Hospital Staff. This free training is accessible by creating an account in Train CT. This platform will allow CT NBS to update content regularly to reflect important changes such as changes to state statutes or additions to the CT's screening panel. There is still time to participate in our pilot testing. To register please go to <https://www.train.org/connecticut/course/1093201/>. We encourage all who play any part in the Newborn Screening Process including **midwives** to take this course!

We can also customize online group trainings specific to the needs of your staff to review data entry procedures, updated state statutes, Maven updates and bloodspot, hearing and CCHD screening procedures. Please email Marie.Burlette@ct.gov to discuss further.

In closing, the CT NBS Program thanks you for all your efforts on behalf of Connecticut's Newborns. Please make use of the updated home birth and NBS Waiver forms attached and discard older versions. Please feel free to contact the CT NBS Program at 860.920.6628 or at dph.nbstracking@ct.gov with any questions or concerns.

Sincerely,

Marie Burlette RN, BSN, MPH
Supervising Nurse Consultant
Connecticut Newborn Screening Program