

# NEWBORN SCREENING COORDINATOR TOOLKIT

*A guide to help you become a successful Newborn Screening Coordinator*

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Center**

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## Section 1: Newborn Screening Overview

### What is the Newborn Screening Program?

#### Introduction

The New York State Newborn Screening Program (NYS NBSP) is a public health service provided to all infants born in NYS for early detection of treatable disorders that can affect newborns or children. The NBSP screens for more than 50 disorders, which without treatment, may permanently impact the health and overall quality of life of newborns. Because the early recognition and treatment of these disorders can be lifesaving, newborn screening is mandated under public health law and written permission from parents is not required to conduct this screening.

#### The Importance of Early Detection

Most babies born with one or more of the disorders on the newborn screening panel appear healthy at birth, and the newborn screen is the first indication that the infant has a health concern. Without this screen, affected infants could experience significant delays in diagnosis and treatment, which can be deadly. However, when the newborn specimen is collected according to NYS regulations, screening has the potential to detect disorders and allow for prompt treatment within days of birth.

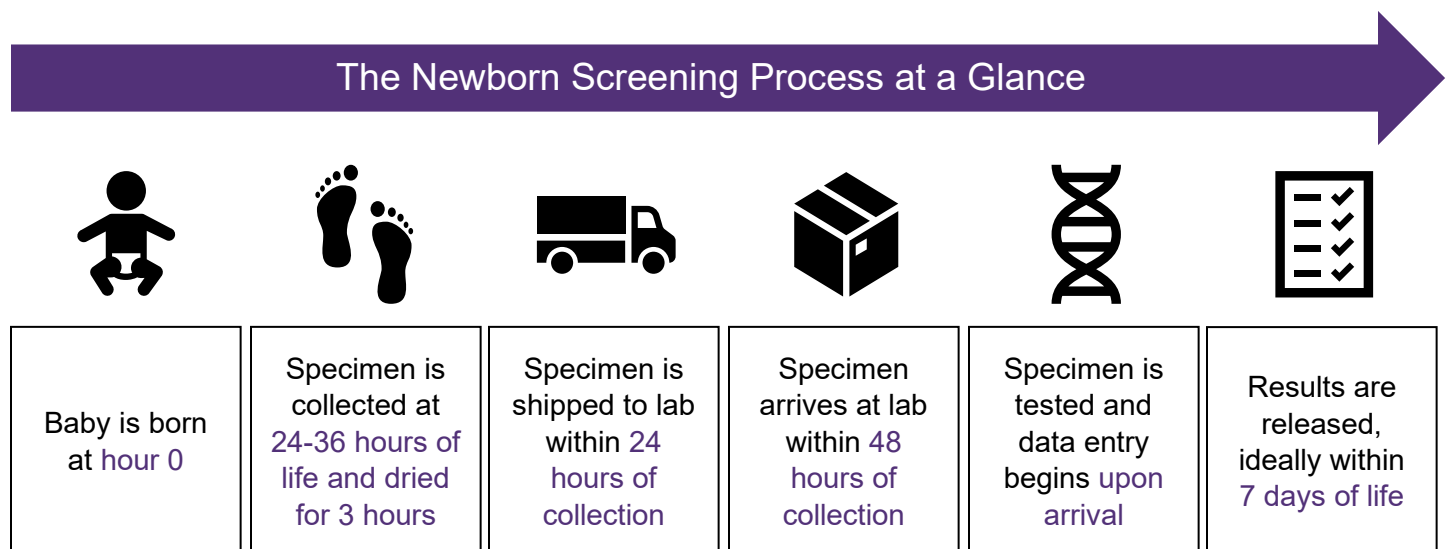
#### What is a Newborn Screening Specimen?

Shortly after birth, a small blood sample is collected from an infant via heel stick. Drops of blood from the heel stick are used to saturate the 5 marked circles on the blood collection form (page 8). This form, with all the marked circles filled in, is the infant's newborn screening specimen which is mailed via overnight courier to the newborn screening lab for testing.

#### Newborn Screen vs. "PKU Test"

Phenylketonuria, or PKU, was one of the first disorders on the newborn screening panel. As a result, some people still refer to the newborn screen as "PKU" or the "PKU test". However, today's newborn screening panel is made up of more than 50 disorders. It is very important to refer to the testing as the "newborn screen" and not the "PKU test" to avoid confusion and prevent providers from ordering incorrect lab tests for critically ill infants.

### The Newborn Screening Process at a Glance



## What is a Newborn Screening Coordinator?

A newborn screening coordinator (NBSC) is a role that is assigned each year by the hospital's CEO to help fulfill the hospital's responsibilities as outlined in the NYS newborn screening regulation, 10 NYCRR 69-1.3. A hospital's NBSC is the main contact for the NBSP.

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*A Newborn Screening Coordinator that is well-organized, communicative, and dedicated to excellent newborn screening compliance is key to ensuring the proper screening, diagnosis, and treatment of newborns.*

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### Responsibilities of a Newborn Screening Coordinator

1. Ensure that the specimen collection card is filled in correctly, completely, and legibly.
2. Resolve discrepancies related to specimen identification, provide missing or illegible data submitted with the specimen, and/or provide follow-up information.
3. Receive unsuitable/sub-optimal specimen reports from the NBSP.
4. Ensure that repeat specimens are submitted after an unsuitable/sub-optimal specimen or borderline newborn screening result is issued, or whenever a repeat specimen is requested.
5. Contact the infant's parents/guardians and post discharge primary care provider (PCP) for notification of the need for a repeat specimen **within 1 day** of learning the result.
6. Document all efforts made to secure a repeat specimen **within 90 days** of receipt of the abnormal result if a repeat specimen cannot be obtained.
7. Ensure the hospital has received newborn screening results for all infants and communicated them to the baby's provider, as applicable.
8. Receive, properly store, and distribute the newborn blood collection forms and newborn screening educational materials. Order additional materials online if the need arises.
9. Communicate with the Department of Health as necessary regarding maternal/newborn HIV testing regulations in the labor, delivery, and nursery settings.

### Prepare for Success

1. Send your hospital affiliation, phone number, fax number, email, and Health Commerce System username to the NBSP via email ([nbsinfo@health.ny.gov](mailto:nbsinfo@health.ny.gov)). This information should also be updated on HERDS in the Health Commerce System (page 30).
2. Request access to your hospital's medical record system if you do not have access already. The NBSP will contact you to clarify missing/illegible demographic information for mother and baby, find updated PCP information, and request follow-up information on cases. Without access to medical records, it will be hard for you to fulfill this responsibility.
3. Familiarize yourself with the current [newborn screening regulations](#).

This toolkit is a detailed guide that will walk you through how to successfully maintain the roles and responsibilities of being a NBSC. However, if you have any questions that are not answered, please call (518) 473-7552 or email [nbsinfo@health.ny.gov](mailto:nbsinfo@health.ny.gov) and we will be happy to assist you.

Welcome to the newborn screening family! We are happy to have you and look forward to working together to keep newborns safe and healthy.

## The Newborn Screening Application

The NBSP has an application available through the Health Commerce System that is an important resource for NBSCs. On the app you will be able to see newborn screening updates and announcements, look up screening results for specimens submitted by your hospital, and view and/or enter notes into an infant's newborn screening case.

### Request Access to the Newborn Screening Application

If you do not have a Health Commerce System account, you can register using the information below:

- Prescribing medical professionals should visit the following site:  
<https://apps.health.ny.gov/pub/top.html>
- Other users should visit <https://apps.health.ny.gov/pub/usertop.html> or call the Health Commerce System Helpdesk at 1-866-529-1890.
  - If you register online, approval is required by a prescribing medical professional or Health Commerce System hospital coordinator to activate your account.
- For issues with passwords or logins, please contact the Health Commerce System Helpdesk at 866-529-1890 or [camu@its.ny.gov](mailto:camu@its.ny.gov). The NBSP cannot create a Health Commerce System account for you, and we can only grant you access to the Newborn Screening Application after you have created a Health Commerce System account.

If you already have a Health Commerce System account, you should email your Health Commerce System username and institutional affiliation to [nsbinfo@health.ny.gov](mailto:nsbinfo@health.ny.gov) and indicate that you would like access to the newborn screening application. Most times, access to the application is granted within one day of the initial request.

### Log in to the Newborn Screening Application

1. Log in to the [Health Commerce System](#)
2. In the “My Applications” menu, scroll down and select the “Newborn Screening Applications” link. Make sure to select the words “Newborn Screening Applications” and not the blue dot to the right.
3. You will be redirected to the homepage of the Newborn Screening Application, where there is a list of laboratory announcements. Please review these periodically as they may change.
4. On the left-hand side of the screen, there is a list of icons and headings. You will primarily be using the Secure Remote Viewer and Case Demographics (also called iCMS).
  - a. The Secure Remote Viewer contains test results for all babies born after 2011, whether screen positive or negative.
  - b. Case Demographics contains information on cases that were either unsuitable, borderline, or referrals which require follow-up actions. You can use Case Demographics to make notes on an infant's case, view notes made by the NBSP, and upload documents.



More detailed information regarding how and when to use the Secure Remote Viewer (page 16) and Case Demographics (page 24) is discussed in this toolkit.

## Section 2: Ordering Newborn Screening Materials

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It is the responsibility of the NBSC to monitor supplies and order more when necessary. These supplies are available at no cost to the hospital. Blood collection forms, brochures, and posters can all be ordered on the NBSP's [website](#).

### Blood Collection Forms

Blood collection forms are shipped to most hospitals quarterly (January, April, July, and October). Each hospital will receive enough blood collection forms to cover the total number of specimens submitted the previous year plus 10%.

Hospitals with fewer than 400 births per year are shipped their annual supply of blood collection forms in October.

If your hospital is running low on blood collection forms, call 518-473-9773 or visit the NBSP [website](#) to order more. Please allow 3-4 business days for supplies to arrive.

### Brochures

Your hospital should have a supply of brochures available as educational tools for parents. All brochures can be ordered in multiple languages.

#### For Your Baby's Health

*For Your Baby's Health* brochures should be given to every parent upon admission for delivery. The brochure provides background on the importance of the newborn screen and what the results could mean for the newborn's health.

#### Trait/Carrier Status

The NBSP offers brochures on trait/carrier status for various disorders. They are a helpful educational tool for parents who have a newborn that has been identified as a carrier for a disorder or as having a disorder trait.

### Posters

There are two posters available on our website to serve as educational tools for hospital staff.

#### Blood Collection and Handling Procedure

This poster describes proper blood collection and handling of the blood collection form. This should be used as a training tool and can be hung in the nursery/NICU as a reminder of proper protocol for staff.

#### Simple Spot Check

This poster shows examples of suboptimal/unsuitable specimens, and the collection mistakes that result in these types of specimens. This should be used as a training tool for all staff who collect specimens.

## Section 3: Educating Parents

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It is important to educate parents about the newborn screen prior to specimen collection. Knowing what to expect, as well as the many benefits of the newborn screen, can help parents feel more comfortable with the screening process. Often, a mother first hears about the newborn screen when she is admitted to the hospital or shortly after delivery.

Upon admission for delivery, please provide the parents with:



**A copy of the NYS Newborn Screening Program's *For Your Baby's Health* brochure.** The brochure is available in many languages and can be ordered at no cost to your hospital from our [website](#).



**General information about the newborn screen**, including that the screen is a free service provided to all newborns in New York State and is crucial in detecting babies that, despite appearing healthy at birth, may have a serious and possibly fatal disorder that requires prompt treatment.



**The pink parent copy of the blood collection form.** Let the parents know that this form should be given to their newborn's PCP at their first appointment. Parents should also be aware that their newborn's PCP can use the Lab I.D. to look up the results of the newborn screen online, which should be available within **7-10 days** of birth.



**Information about what to expect after the screen.** Discuss with parents that, while unlikely, there is a chance that their newborn will need another newborn screen. Encourage the parents to have the repeat screen collected in a timely manner, if requested.

Although parents should provide their newborn's PCP with the pink copy of the blood collection form, it is the responsibility of the hospital, as outlined in our current newborn screening regulations, to also provide the newborn's PCP with the Lab I.D. of the screen. The Lab I.D. should be included in the infant's discharge summary and sent to the PCP. Please ensure that the Lab I.D. can be easily located in the discharge summary.

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*It is critical that the Lab I.D. for every infant born at your hospital be included in the infant's discharge summary and sent to their post-discharge provider.*

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## Collecting the Newborn Screening Specimen

### Collection in the Nursery

Collecting a specimen properly is key to timely and efficient testing. Please confirm that all staff are thoroughly trained on proper specimen collection techniques before collecting any specimens.

Training on specimen collection must occur **annually** for all staff, and completion of training must be documented and made available to the NBSP upon request.

1. Collect blood 24-36 hours after birth. Ensure that your hospital has a protocol in place to collect a newborn screening specimen on <b>every</b> infant born at your hospital.
2. Place infant's leg in position to increase venous pressure.
3. Warm heel for three minutes.
4. Cleanse puncture site with sterile alcohol pad.
5. Wipe dry with sterile gauze.
6. See diagram on blood collection form for puncture site. Avoid previous puncture sites or curvature of the heel.
7. Puncture heel using no longer than a 2mm sterile lancet.
8. Wipe away first drop of blood with dry sterile gauze.
9. Allow second, larger drop of blood to form.
10. Gently apply filter paper to large drop of blood, allowing blood to soak through and completely fill preprinted circle. Specimen may be collected on either side of the filter paper but should NOT be applied to BOTH sides. Do NOT use capillary tubes or syringes for specimen collection.
11. Apply one drop of blood per circle. Do not layer successive drops of blood or touch the heel to the same circle multiple times.
12. Fill all five circles.
13. To prevent contamination, avoid touching the special absorbent paper used for collecting the blood specimen. Only blood should come in contact with the paper.
14. Allow blood spots to air dry thoroughly for at least 3 hours on a flat, nonabsorbent surface, away from direct heat and sunlight. Avoid touching or smearing blood spots. Never superimpose one filter paper on another before thoroughly drying. Once blood spots are completely dry, place the protective cover over blood. Do not refrigerate.
15. For hospitals only: Place in UPS Interior Security Pack along with a transport form (link available on page 15) and place inside of UPS newborn screening paper envelope or box.
16. Submit thoroughly dried collection forms to the testing laboratory as soon as possible, within 24 hours of collection.
17. If submitting data electronically, affix approved data label to each copy of this form in the red-outlined area only.

These specimen collection instructions are also located on the back of every blood collection form. Be sure to visit our [website](#) for more information on specimen collection.

## Collection in the NICU

Though the specimen collection technique is the same for NICU and nursery babies, the timing of the first collection and the number of screens needed differs for NICU babies. In general, a newborn in the NICU will require 3 newborn screens:

1. If a newborn requires admission to the NICU prior to the collection of an initial newborn screen, a screen should be collected **at admission** prior to interventions (blood transfusions/TPN)
2. A repeat screen should be collected at **48-72 hours** of life
3. A third screen should be collected at **discharge or 28 days** after birth (whichever comes first)

If during this process the NBSP requests that a repeat specimen be collected, collect the repeat as soon as possible. Do not wait for discharge or 28 days of life. For example, if a NICU baby has a borderline result, collect a repeat specimen as soon as requested, regardless of the newborn's age.

When filling out the blood collection form for the second and third screens for a NICU baby, please be sure to check the "repeat specimen" box at the top right of the blood collection form and fill out the "Previous Lab ID #" boxes at the bottom left of the blood collection form before submission. This will allow us to correctly interpret results and will also help us link specimens in our system so we know that the baby has received all required screens.

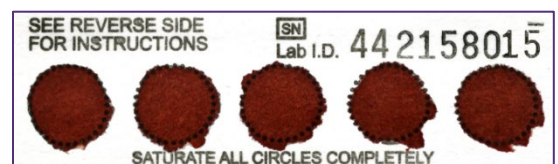
If the initial newborn screen is not collected prior to the start of TPN/Transfusions:

1. The initial newborn screen should be **collected 72 hours after administration** of transfusion and/or TPN
2. A repeat specimen should be collected **at least 120 days after the final transfusion** and/or TPN

If newborns are admitted to your hospital's Special Care Nursery, and are not receiving TPN or transfusions, they may follow the nursery collection protocol on the previous page.

## The Perfect Specimen

- Has **all** of the requested information correctly and legibly recorded on the blood collection form
  - OR if submitting electronically, has **ONLY** the infant's last name handwritten on the form and has the label applied to the form in the correct location and orientation
- Has the correct PCP indicated
- Has the correct time of birth, in military time
- Has the correct time of collection, in military time
- Is collected within the proper timeframe
- Has no foreign contaminants on the filter paper
- Has all printed circles completely filled with blood that is applied evenly on **one side** of the filter paper, free of layering and clots
- Is dried for at least **three hours** on a flat, clean, non-absorbent surface, away from direct heat and sunlight
- Has been examined and approved by an experienced staff member
- Is covered by the safety flap after proper drying and before mailing
- Is delivered to the appropriate pick-up site within the hospital for delivery to the screening laboratory the next morning. If your site does not participate in the NYS delivery program (non-hospital) the specimen must be sent to the NBSP by first class mail or its equivalent within 24 hours of collection



### Special Circumstances: Early Discharge of a Baby

If a newborn is discharged from the hospital at less than 24 hours of life, the birth hospital **should collect a specimen prior to discharge**. Although specimens collected prior to 24 hours of life will need to be repeated, they can still be tested for some disorders and will show emergency-level results for all disorders. Before the parents leave the hospital, please schedule a time for them to return with the baby between **48-72 hours of life** to have a repeat screen collected.

If the parents refuse to have a less than 24-hour screen collected prior to discharge, please fill out a blood collection form for the infant. Although the blood collection form will not have any blood on it, the NBSP will be able to create a case for the infant using the demographic information on the form. Additionally, the provided information can help the NBSP to follow-up with the family to ensure that a screen is collected. On the bottom of the blood collection form, in the notes section, please write a brief description of why the form has no blood specimen.

**Example:** If baby will have the initial blood specimen collected by PCP write “defer to PCP”.

**Example:** If baby will return to have the initial blood specimen collected by hospital write “returning to hospital of birth”.

### Special Circumstances: Late Admission of a Baby

If a baby is admitted to your hospital within the first 28 days of life, and a prior screen cannot be located, your hospital should collect a specimen upon admission. On the blood collection form, select “No” under Hospital of Birth if the baby was not born at your hospital. If you know where the baby was born, please include that information in the notes section of the blood collection form.

### Special Circumstances: Transfer of a Baby to Another Hospital

Sometimes an infant will have to be transferred from your hospital to another hospital’s NICU for advanced care. In this case, the hospital of birth should collect the initial newborn screening specimen and notify the receiving hospital of the collection by providing them with the LabID from the screen. In the notes section of the blood collection form, the birth hospital should write where the baby was transferred.

If the baby is transferred to a hospital without having an initial newborn screening specimen collected, it is the responsibility of the birth hospital to:

1. Notify the receiving hospital that no newborn screening specimen has been collected
2. Submit a blood collection form to the NBSP with all the demographic information completed and with a note indicating where the baby was transferred. This will let the NBSP know that the baby was born, and who to contact for follow-up.

The receiving hospital is then responsible for collecting any repeat screens and conducting any needed follow-up. The receiving hospital should follow the recommended procedure for NICU admissions.

## Unsuitable and Sub-optimal Specimens

Proper specimen collection techniques are crucial for collecting specimens that are suitable for testing by the NBSP laboratory. Approximately 2-3% of the specimens received by the NBSP are either unsuitable or sub-optimal for testing. These specimens are known to produce erroneous laboratory results and must be repeated, which delays the screening process and puts newborns at unnecessary risk for harm should they have one of the disorders on the screening panel.

### Sub-optimal vs. Unsuitable Specimens

Although these labels are often used interchangeably to describe poor quality specimens that need to be repeated, they are different.

Specimens may be considered suboptimal if they exhibit serum rings, clotting, or if they are not properly dried prior to mailing. Although sub-optimal specimens are tested at the NBSP lab and results are issued for some disorders, a repeat specimen is required due to poor sample quality. To achieve timeliness goals, infants with abnormal results on sub-optimal specimens will be referred for care, but a repeat specimen is still required.

An unsuitable specimen, sometimes referred to as a “true unsuitable” is a specimen with no blood, an insufficient quantity of blood, or a specimen that is diluted, discolored, or contaminated. Specimens that are damaged in transit or are also unsuitable. These specimens cannot be tested for **any** disorders.

### Improving Your Unsuitable Specimen Rate

You can check your hospital’s unsuitable specimen rate in the “Unsuitable Specimens” column on your hospital’s monthly report cards. Although the column is labeled “Unsuitable Specimens”, it does include your hospital’s sub-optimal specimen compliance as well. It is recommended that you review at least the most recent 6 months of report cards to get a better understanding of your hospital’s unsuitable specimen compliance.

To improve your unsuitable specimen rate:

- Fully train all staff on specimen collection before they collect newborn screening specimens
- Repeat specimen collection training annually
  - A specimen collection video can be found on our [website](#)
  - Have a specimen collection demonstration by a well-practiced staff member
- Do not touch the special absorbent filter paper where the blood spots are collected
- Ensure that all specimens are dried in a safe, secure place free from direct heat and contaminants such as hand sanitizer, lotion, etc.
- Dry all specimens for at least 3 hours prior to packaging and shipping

To find out which types of unsuitable and sub-optimal specimens your hospital submits most often, please contact the NBSP via email at [nbsinfo@health.ny.gov](mailto:nbsinfo@health.ny.gov).

**Coming soon:** The Newborn Screening Program is in the process of launching a Hospital Communication Portal through the Health Commerce System, where your hospital can access yearly summaries of your unsuitable data and other newborn screening metrics.



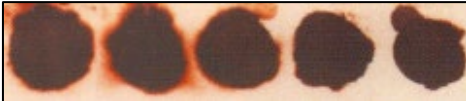
## Causes of Unsuitable and Sub-optimal Specimens

### Unsuitable Specimens



**Specimen quantity insufficient for testing.**

- Removing filter paper before blood has completely filled circle or before blood has soaked through to second side.
- Applying blood to filter paper with a capillary tube.
- Allowing filter paper to come into contact with gloved or ungloved hands or substances such as hand lotion or powder, either before or after blood specimen collection.



**Specimen appears diluted, discolored, or contaminated.**

- Squeezing or “milking” of area surrounding the puncture site.
- Allowing filter paper to come into contact with gloved or ungloved hands or substances such as alcohol, formula, antiseptic solutions, water, hand lotion or powder, etc., either before or after blood specimen collection.
- Exposing blood spots to direct heat.

### Sub-optimal Specimens



**Specimen not dried before mailing.**

- Mailing specimen before drying for a minimum of three hours.



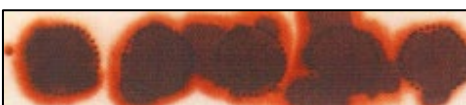
**Specimen appears supersaturated.**

- Applying excess blood to filter paper, usually with a device.
- Applying blood to both sides of filter paper.



**Specimen appears scratched or abraded.**

- Applying blood with a capillary tube or other device.



**Specimen exhibits serum rings.**

- Not wiping alcohol from puncture site before making skin puncture.
- Allowing filter paper to come into contact with alcohol, hand lotion, etc.
- Squeezing area surrounding puncture site excessively.
- Drying specimen improperly.
- Applying blood to filter paper with a capillary tube.



**Specimen appears clotted or layered.**

- Touching the same circle on filter paper to blood drop several times.
- Filling circle on both sides of filter paper.

## Exemptions to Specimen Collection

Newborn screening is mandated by law, and parental permission is not required to collect a newborn screening specimen on an infant. However, there are two circumstances where newborn screening is exempt:

- 1 The parent or guardian of the infant is a member of a recognized religious organization whose teachings are contrary to the testing requirement, and he or she has declined the testing of their child.

If a parent or guardian objects to testing based on religious grounds, the hospital administrator, or another person designated to register the birth of the child (as defined by Public Health Law Section 4130) has the following responsibilities:

- Fully inform the parent or guardian of the consequences of refusal.
- Inform the NBSP of the parental refusal by submission of a signed [refusal of newborn screening for religious reasons form](#) or a similar document.
  - This form must include a statement indicating that the parent or guardian is a member of a recognized religious organization and has been fully informed of the benefits of screening as well as the possible consequences of not having the newborn tested.
  - Keep a copy of this refusal form in the baby's health record at the birth hospital.
- Submit the Newborn Screening Blood Collection Form with complete demographic information, but without the blood sample, to the NBSP.
  - "Declined testing" should be written in the "Notes" box, the green copy should be retained by the hospital, and the pink copy given to the parents.

- 2 The newborn is receiving compassionate (comfort) care only, and is not expected to survive, and the screening has been declined by the parent or guardian.

As above, the attending physician must:

- Submit a Newborn Screening Blood Collection Form with complete demographic information, but without a blood sample. This is to be accompanied by written documentation of the reason for compassionate care and parental declination of screening.
- Explain to the parent or guardian that even in such a case, there may be a benefit to newborn screening. Screening results may shed light on the cause of the newborn's medical condition and the remaining blood spots would be stored, providing the opportunity for future testing if the diagnosis remains unclear.

## Section 5: Specimen Shipping

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### Shipping Newborn Screening Specimens

1. Dry specimens for at least 3 hours on a flat, non-absorbent surface away from direct sunlight and potential contaminants.
2. Package all dry specimens to be shipped in a UPS security pack, seal and place the pack in the envelopes or provided by UPS.
3. Print out a UPS label each day. Once a label is made, the package will appear in the UPS system.
4. If directly mailing, address all envelopes and boxes to:  
Newborn Screening Program  
NYS Department of Health / Wadsworth Center  
120 New Scotland Avenue Albany, NY 12208
5. If specimens are shipped on a Friday, check the “Saturday Delivery” in Campus Ship.
6. Ship specimens within 24 hours of collection to ensure timely testing.
7. Record each specimen's Lab ID on the [Newborn Screening Transport Form](#) and write the total number of specimens you are sending in the circle on the transport form.
8. Complete the form with your information and the UPS tracking number. Make a copy to keep for your records and put the original copy in the UPS newborn screening envelope or box.
9. Confirm that all specimens to be shipped are at the designated UPS pick up site prior to your hospital's pickup time. Each hospital's pickup time should be displayed on the UPS placard at the pickup site.

### Tracking Specimens

All hospitals should have a written policy regarding specimen tracking. A staff member at your organization should be consistently tracking all shipments to ensure they are received at the NBSP laboratory within 48 hours of collection. There are two ways to track envelopes:

1. Navigate to the UPS tracking [website](#).
  - a. Enter the UPS tracking number of the envelope.
  - b. Check to see if the package is delivered. You can also select “View Details” to see more information about the time of pickup from the hospital and delivery to the laboratory.
2. Enter the 9-digit LabID of each specimen documented in the tracking log into the Secure Remote Viewer. If there is no record of the specimens at our facility, it is likely that the package has not yet arrived. More information regarding the Secure Remote Viewer can be found in the next section of the toolkit.

If a package appears to be delayed or lost in transit, please reach out to our Accessioning Supervisor by phone or email: Fred Zielinski, [alfred.zielinski2@health.ny.gov](mailto:alfred.zielinski2@health.ny.gov), 518-474-6310. **Your hospital will not be penalized for any specimens that are lost or damaged in transit by UPS.**

### Specimens Missing in Transit

If an envelope is in fact missing in transit, the NBSP will inform you by phone and/or email and request that you:

1. Let the NBSP know how many specimens were included in the envelope according to the information documented on the Newborn Screening Transport Form.
2. Fill out a Specimens Missing in Transit form (which will be provided to you) for each specimen included in the missing envelope OR submit scanned images of the green submitter's copies for each specimen included in the missing envelope.
3. For all newborns whose specimens were in the missing envelope, contact their parents **within 24 hours** to arrange for repeat screens.



## Section 6: Newborn Screening Results

### Accessing Newborn Screening Results

It is the responsibility of the NBSC to view and document newborn screening results for every newborn screen submitted by their hospital.

Results for all infants can be found, viewed, and printed on the Secure Remote Viewer (SRV), which is part of the newborn screening application. The SRV also allows you to see if a specimen has arrived at the NBSP lab and is in the process of being tested. The SRV is available 24 hours a day, 7 days a week and has results for all infants screened in New York after 2011. If older results are needed, they can be requested from the NBSP via a [record request form](#).

#### Navigating the Secure Remote Viewer (SRV)

1. Log in to the Health Commerce System and then select Newborn Screening Applications.
2. Select the “Secure Remote Viewer” icon.



3. The search window will be displayed:

Lab ID #	<input type="text"/>
Birth Hospital	<input type="text" value="v"/>
Date of Birth	<input type="text" value="v"/>
Infant's Last Name	<input type="text"/>
Mother's Last Name	<input type="text"/>
Mom's First Name	<input type="text"/>
Medical Record #	<input type="text"/>
Date Reported	<input type="text" value="v"/>
<input type="button" value="Search"/> <input type="button" value="Clear"/>	

4. To look up the most recent results for all babies born at your hospital, select your hospital in the **Birth Hospital** field and select yesterday's date in the **Date Reported** field and select "**Search**".
  - a. Example: If I am looking up results on 4/22/2021, I will enter 4/21/2021 in the **Date Reported** field.
  - b. Please note that no results are released on the weekend or on state holidays. Therefore, when you look up results on a Monday, enter the date of the previous Friday to see the most recent results.
    - i. Example: If I am looking up results on Monday, 4/19/2021, I will enter the date of the previous Friday, 4/16/2021, in the **Date Reported** field.

5. A list of babies will be generated. Select **Check All** at the top of the list and **View Mailer** at the bottom of the list. A pdf file of all results will download onto your computer.
6. To download one result at a time, check the box next to the baby's name and select **View Mailer**. The pdf file of the result will download onto your computer.
7. Document the results per your hospital's protocol and ensure to notify the infant's doctor of the results and any required follow-up actions. See page 18 for more information on documenting results.

If performed daily, the steps above will ensure that you have a complete record of all screening results for your hospital. Viewing and documenting these newborn screening results is an extremely important responsibility of the NBSC.

NBSCs can also look up results for a baby individually. There are three ways to do this:

1. Enter ONLY the baby's LabID number and select **Search**.
2. Enter ONLY the baby's Medical Record Number and select **Search**.
3. If you do not have the baby's LabID or Medical Record Number, you can enter the mother's last name, baby's date of birth, and birth hospital. ONLY enter these fields and select **Search**.

The next screen will show you pertinent demographic information about the baby, including LabID number, name, date of birth, mother's name, hospital, and collection date. The final column on the screen "Results Ready" with either a Y or a N. The Y means that the results are ready to be viewed, and the N means that the specimen has arrived at our lab but is still being tested.

**If you are unable to find a screen using this method, please call the NBSP at 518-473-7552 for help locating the baby's LabID.**

When using the SRV, you may encounter an error message that says **Enter Custom Message for SRV Here**. If this happens, please either call the NBSP at 518-473-7552 or email [nbsinfo@health.ny.gov](mailto:nbsinfo@health.ny.gov) to notify us so we can reboot the SRV software. This is an easy fix but we may not know it needs to be done unless you tell us.

**Please note:** It takes **5-7 days** after the specimen arrives at our lab for all testing to be completed.

## Documenting Results

Your hospital should have a protocol in place to ensure that every newborn is screened and that the results of those screens are viewed and documented. Although the details of that protocol are at the discretion of the hospital, you may find it helpful to use a specimen collection and tracking log. A specimen collection and tracking log can be used to record important information about each specimen collection, track the shipping information for each specimen, and record screening results and necessary follow-up efforts.

Please find an example specimen collection and tracking log below:

Birth Facility Newborn Screening Collection Log															
Infant's Name (Last, First)	Date of Birth @ Time of Birth	LABID	Medical Record #	Planned Health Care Provider After Discharge	Date of Collection @ Time of Collection	Collector Initials	Specimen Quality Reviewed ?	Demographics on Blood Collection Form Reviewed?	Courier Pick-up Date & Tracking #	Date NBS Results Accessed	NBS Results	Repeat Needed?	PCP Contacted for Repeat	Parent Contacted for Repeat	Follow-up Efforts Recorded in iCMS?
<b>EXAMPLE:</b> Smith, John	2/1/21 @ 1306	489756321	7894572	Dr. Brian Williams	2/2/21 @ 1309	MK	Yes	Yes	2/3/21 – hy783js0194kgt781	2/8/21	Borderline Thyroid	Yes	Phone call to Dr. William's office 2/8/21, left message notifying him of needed repeat	Phone call to mother of baby 2/8/21, she will bring baby to the PCP for the repeat	Yes
<b>EXAMPLE:</b> Brown, Jane	2/1/21 @ 1915	489586235	4561542	Dr. Jessica Jones	2/2/21 @ 1922	MK	Yes	Yes	2/3/21 – hy783js019kgjt781	2/8/2021	Sub-optimal	Yes	Phone call to Dr. Jones, 2/8/21, she will collect the repeat.  Phone call from Dr. Jones 2/17/21 – repeat specimen was submitted and results are normal.	Phone call to mother of baby 2/8/21, she will follow-up with Dr. Jones.	Yes
<b>EXAMPLE:</b> Davis, Jill	2/4/21 @ 0847	486529789	9256811	Dr. Tom Miller	2/5/21 @ 0910	MK	Yes	Yes	2/5/21 – lk987hy6af1524th6	2/10/21	All Results Negative	No			

## Interpreting Results

A newborn's screening result, also referred to as a **mailer**, will include key demographic information for the newborn as well as a summary of the results and any required actions. The reverse side of the mailer has a full list of all screened disorders and reference ranges.

It's important to note that the newborn screen is not diagnostic. If the NBSP identifies a baby with the potential for one of the disorders, the baby will be referred to a specialty care center (SCC) for an evaluation and a final diagnosis.

**Normal Result:** Normal results are frequently referred to as WAL, which stands for within acceptable limits. These results should be documented for the infant and relayed to the PCP, but no further action is required from the hospital of birth. Mailers for normal results are 1 page long when printed. Mailers display demographic information for the infant, as well as a list of screened disorders (on the reverse side).

Example of mailer for normal results (excluding protected health information).

Page 1.

<p><b>NEW YORK STATE DEPARTMENT OF HEALTH</b>          Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208          Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937          Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845</p>		
<p>Infant:          Birth Date:          Multiple Birth:          Med Rec #:          Specimen Date:          Date Received:          Date Reported:</p>	<p>Lab ID:          Accession #:          Prior Accession #:          Mother:</p>	<p>Submitter:          Hospital:</p>
<p><b>ALL TESTS SCREEN-NEGATIVE</b>  <b>NO FOLLOW-UP ACTION REQUIRED</b></p> <p>SEE REVERSE SIDE FOR SCREENED DISORDERS AND REFERENCE RANGES</p>		

**Trait/Carrier Detected:** A trait or carrier status may be reported for conditions such as hemoglobin disorders or cystic fibrosis. A newborn who is a carrier for a disorder or has a disorder trait will likely never experience any symptoms or require any care. These results should be documented, but no further action is required from the hospital of birth and no repeat screen is required. Mailers for trait/carrier results are 2 pages long when printed. Mailers display demographic information for the infant, as well as a list of screened disorders (on the reverse side of page 1).

Example of a mailer for Sickle Cell Trait.

Page 1.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>SCREEN POSITIVE NEWBORN SCREENING RESULT</b>		
<u>DISORDER</u>	<u>SCREENING RESULT</u>	<u>EXPECTED RANGE – See Page 2</u>
Disorder name	Screen Negative	
Disorder name	Screen Negative	
<b>Hemoglobin</b>	<b>Trait Detected</b>	
Disorder name	Screen Negative	

Page 2.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>Comments</b>		
<p><b>Hemoglobin:</b> HGB F, HGB A, and HGB S; Consistent with Sickle Cell Trait. It is recommended that the parents are advised of this result and referred for education and/or genetic counseling as needed.</p>		

**Sub-optimal Specimen:** A sub-optimal specimen is tested for all disorders, but a repeat specimen is required as soon as possible due to the poor quality and unreliability of the sub-optimal specimen. It is the responsibility of the hospital of birth to notify the infant's PCP and guardians that a repeat specimen is required within 1 day of learning of the result. Mailers for sub-optimal specimens are 2 pages long when printed. Mailers display demographic information for the infant, as well as a list of screened disorders (on the reverse side of page 1).

Example of mailer for a sub-optimal specimen.

Page 1.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue. Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender:	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>REPEAT SPECIMEN REQUIRED</b>		
<u>DISORDER</u>	<u>SCREENING RESULT</u>	<u>EXPECTED RANGE – See Page 2</u>
Disorder name	<b>Suboptimal for testing – See Comments</b>	
Disorder name	Screen Negative	
Disorder name	Screen Negative	
Disorder name	<b>Suboptimal for testing – See Comments</b>	
Disorder name	<b>Suboptimal for testing – See Comments</b>	

Page 2.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender:	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>Comments</b>		
Specimen appeared clotted or layered and was suboptimal for testing.		
<b>A REPEAT SPECIMEN IS REQUIRED.</b>		

**Borderline Result:** A borderline result refers to a value that is not in the normal range for the disorder but is not in the referral range. Borderline results require a repeat specimen as soon as possible. For some borderline results, a PCP can complete independent lab tests and send the results to the NBSP in lieu of a repeat specimen. It is the responsibility of the hospital of birth to notify the infant's PCP and guardian(s) that a repeat specimen is required within 1 day of learning the result. Mailers for borderline results are 2 pages long when printed. Mailers display demographic information for the infant, as well as a list of screened disorders (on the reverse side of page 1).

Example of a mailer for a borderline hypothyroidism result.  
Page 1.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>SCREEN POSITIVE NEWBORN SCREENING RESULT REPEAT SPECIMEN REQUIRED</b>		
<u>DISORDER</u>	<u>SCREENING RESULT</u>	<u>EXPECTED RANGE – See Page 2</u>
<b>Hypothyroidism</b>	<b>Borderline – See Comments</b>	
Disorder name	Screen Negative	
Disorder name	Screen Negative	

Page 2.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>Comments</b>		
<hr/> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p><b>Hypothyroidism:</b> Slightly elevated level of TSH. A repeat newborn screen specimen or serum thyroid function tests are required.</p> </div>		

**Referrals:** A referral result is a value that is clearly abnormal, above the referral cut-off, and requires independent testing and/or evaluation with a specialist. Referrals are identified and provided to NBSP Follow-up staff by NBSP Laboratory staff. Results in the referral range are available before the entire panel is tested, typically within 1 day of the screen being received. In the case of a referral, results are delivered via phone call to the SCC and the newborn's PCP. If the PCP is unknown, the NBSP will contact the NBSC at the hospital of birth for help locating the proper provider. Mailers for referral results are 2 pages long when printed, except for mailers with molecular testing included, which are 3 pages long when printed. Mailers display demographic information for the infant, as well as a list of screened disorders (on the reverse side of page 1).

Example of a mailer for a hypothyroid referral.  
Page 1.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>SCREEN POSITIVE NEWBORN SCREENING RESULT</b>		
<b>PROMPT CONSULTATION WITH SPECIALTY TREATMENT CENTER REQUIRED</b>		
<u>DISORDER</u>	<u>SCREENING RESULT</u>	<u>EXPECTED RANGE – See Page 2</u>
<b>Hypothyroidism</b>	<b>Abnormal/Disease – See Comments</b>	Value
Disorder name	Screen Negative	
Disorder name	Screen Negative	

Page 2.

<b>NEW YORK STATE DEPARTMENT OF HEALTH</b>		
Newborn Screening Program – Wadsworth Center – David Axelrod Institute, 120 New Scotland Ave, Albany, NY 12208 Phone: (518) 473-7552, Fax: (518) 474-0405 CLIA # 33D2005937 Center for Medical Sciences, 150 A New Scotland Avenue, Albany, NY 12208 CLIA # 33D2180845		
Infant:	Lab ID:	Submitter Code:
Gender	Accession #:	Hospital:
Birth Date:	Prior Accession #:	City:
Mother:	Specimen Date:	Med Rec No:
Address:	Date Received:	Physician:
Telephone:	Date Reported:	
	Multiple Birth:	
<b>Comments</b>		
<b>Hypothyroidism:</b> Consistent with primary hypothyroidism.		
Preliminary results for T4 and TSH reported by telephone to Specialty Care Center (SCC) on 1/4/2020.		



## Section 7: The Follow-up Process

---

### What is Follow-up (FU)?

Follow-up (FU) refers to any action a NBSC takes to ensure that a repeat screen is collected from newborns needing additional testing.

### Follow-up Required for Borderline, Unsuitable, and Sub-optimal Specimens

A repeat newborn screening specimen must be submitted for all specimens that are borderline, unsuitable, or sub-optimal for testing. It is the responsibility of the NBSC to:

1. Look up and document **all** results for screens submitted by their hospital.
2. For unsuitable, sub-optimal, and borderline results:
  - a. Notify both the infant's PCP and the infant's guardians of the need for a repeat newborn screening specimen within 1 business day of learning the results.
  - b. Inform the NBSP of their follow-up efforts, including the date of contact, type of contact (phone, mail, etc.), who was contacted, and any response received from the PCP or infant's guardians. NBSCs must provide documentation of their follow-up efforts to the NBSP **within 90 days** of learning the results of the screen if a repeat has not been collected.

We understand that in some instances, despite your best efforts, a repeat screen will not be collected. Although unfortunate, the situation will not be held against you. If you have documented all cases that need repeat screens, contacted the infant's PCP and guardians, and have notified the NBSP of your follow-up efforts, then you have fulfilled your responsibilities as the NBSC.

### Follow-up Required for Referrals

Generally, it is the responsibility of the infant's PCP and the assigned SCC to handle follow-up duties related to referrals. However, the NBSP may contact you for help finding contact information for either the infant's PCP or guardians.

### Follow-up Required for Traits/Carriers

Generally, it is the responsibility of the infant's PCP to inform the family of the trait/carrier status and refer the family to genetic counseling when necessary. The hospital of birth will receive a letter and informational brochure for sickle trait and cystic fibrosis carriers. The hospital should document the result but does not need to conduct any follow-up on the case.

### Case Demographics (iCMS)

The NBSP utilizes a software program called the Case Management System to track and handle cases requiring follow-up (i.e., any cases that have unsuitable, borderline, or referral-level results). There is an internet-based version of this software called iCMS (Internet Case Management System) that is available within the newborn screening application. iCMS allows hospital staff to view most aspects of a baby's newborn screening case exactly as NBSP staff see it. It also gives hospital staff the ability to enter important case information and updates directly into the case without having to mail, fax, or call the NBSP.

iCMS only contains records for babies requiring follow-up, and therefore does not contain records for any babies with screen negative results.

To access iCMS:

1. Log in to the Health Commerce System website and the newborn screening application, then select the **Case Demographics** icon.



2. The following search window will be displayed:

Lab ID #	<input type="text"/>
Birth Hospital	<input type="text" value="v"/>
Date of Birth	<input type="text" value="v"/>
Infant's Last Name	<input type="text"/>
Mother's Last Name	<input type="text"/>
Mom's First Name	<input type="text"/>
Medical Record #	<input type="text"/>
<input type="button" value="Search"/> <input type="button" value="Reset"/>	

3. Search for the case you would like to view. There are two ways to do this:
  - a. Enter ONLY the Lab ID or Medical Record Number and select **Search**.
  - b. Enter ONLY the mother's last name, child's date of birth, and birth hospital and select **Search**.
4. When the record comes up, choose the blue **Select** link on the left.
5. This will bring you to the iCMS home screen in the case.

### iCMS Home Screen:

1. The baby's mother's information, including address and phone number will be shown.
2. In the upper right of the window, there is a "Screen X of \_\_\_", "Prev" and "Next" which indicates how many specimens the baby has had. If there is more than one, the arrows can be used to move between the specimens.
3. The blue box at the top contains basic information about the baby, including mother's name, date of birth, birth order, sex, lab ID and accession number, and the PCP provided on the specimen collection card.
4. This section also provides the case status - open or closed. If the case status is listed as closed it is likely we do not require any additional casework, but please review the notebooks and most recent result to be sure.
5. "Cancel" or "Retry" on the upper right of the screen closes out the case and returns you to the search screen.

### iCMS Notebook:

1. The "Notebook" field can be accessed by selecting the link in the "Case Information" menu on the left of the screen. These are case notes. You can read all previous notebooks to see what has been done on the case and you can add your own comments by scrolling to the bottom and selecting "Add Note." This will likely be the iCMS feature that you use the most. Please add any information that will assist with case management.

Here are some examples of helpful updates:

- a. Calls made or letters sent to the family to get a repeat. Stipulate what happens when you make the call (examples: phone out of order or you left a message, and it was never returned).
  - b. Calls or letters to PCP, add the date of contact and what was included in the letter/discussed on the phone call
  - c. Changes in any demographic info
  - d. New PCP name and phone number
  - e. Baby's AKA (new, legal name)
  - f. Notice that the baby has passed away
  - g. Note that all the above replaces information requested on the "Follow Up Summary Form" we mail to you, so there is no need for you to complete the form and fax it to us.
2. Please include your name at the end of your notebook entry, as on our end it only appears as 'Web User,' and select "save." Once you've completed your note and saved it, it becomes part of that baby's record.
  3. When you enter a notebook, NBSP staff receive an alert. This ensures a review of your notebook will occur by the staff within 24 hours.

### **iCMS Image Capture:**

1. The "Image Capture" field can be accessed by selecting the link in the "Case Information" menu on the left of the screen. This feature allows you to view documents that have been uploaded to the case by selecting the little magnifying glass. In addition, you can upload files to the case. Examples of helpful information that may be uploaded include:
  - a. Independent lab results to follow-up on a borderline result
  - b. Letters sent to parents and/or PCPs notifying them a repeat is needed.

### **iCMS Provider:**

1. The "Provider" field can be accessed by selecting the link in the "Case Information" menu on the left of the screen. This field lists who the NBSP believes to be the baby's current PCP. If more than one provider is listed, the bottom one is the current PCP.
2. If the PCP listed here is incorrect, please add a Notebook to the child's case indicating the name and phone number of the correct provider.

### **iCMS Laboratory Results:**

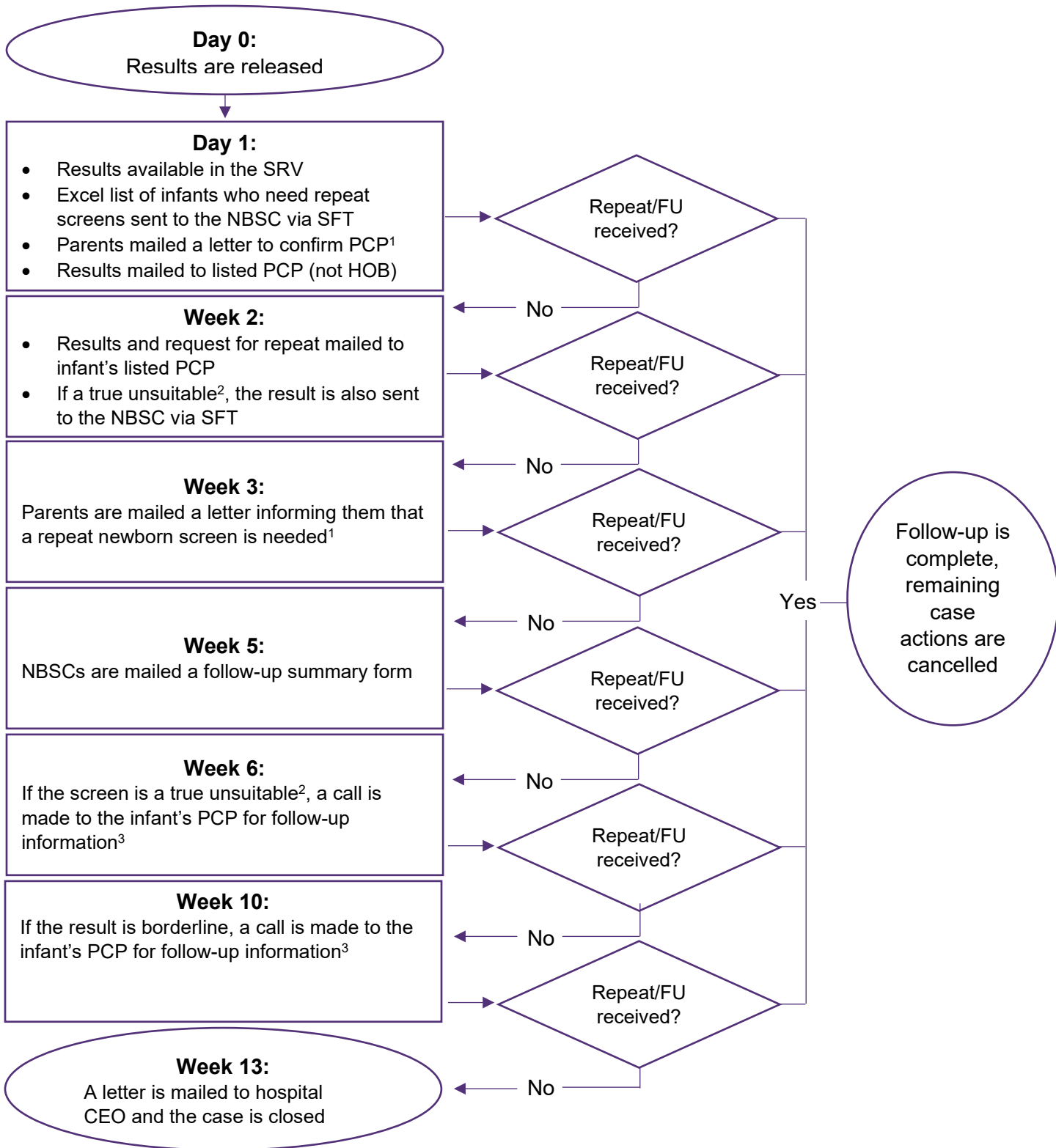
1. The "Laboratory Results" field can be accessed by selecting the link in the "Laboratory Information" box on the left of the screen. This can be used to download and/or print a copy of the child's newborn screening report. To do so, click the little magnifying glass. To print, select the printer icon to left of "Close this window to Return" on top.

If you have any questions about the newborn screening application or iCMS, please call the NBSP at 518-473-7552 or email us at [nbsinfo@health.ny.gov](mailto:nbsinfo@health.ny.gov).

**Note:** Although entering follow-up notes in Case Demographics (iCMS) is the preferred method of follow-up documentation, you can also submit documentation to the NBSP by phone call or by faxing a completed [follow-up summary form](#) for the case.

## The Newborn Screening Program’s Follow-up Process

Although it is the hospital of birth’s responsibility to look up screening results and conduct any necessary follow-up, the NBSP does contact the hospital of birth as well as the infant’s PCP and parents when a repeat screen is needed. The NBSP’s follow-up actions are detailed in the process map below:



1. Parent letters are mailed for Non-NICU babies only.
2. A screen is a true unsuitable if the blood quantity is insufficient, there is no blood, or it is diluted/contaminated.
3. If the infant’s PCP is unknown, the NBSC at the hospital of birth is called.

## Notification of Needed Repeats via Secure File Transfer (SFT)

Most repeat requests are sent to NBSCs via Secure File Transfer (SFT). This is an application available through the Health Commerce System that allows users to send protected health information securely. **The NBSP cannot send you packages through the SFT without your Health Commerce System ID. You can send your Health Commerce System ID to the NBSP via email at nbsinfo@health.ny.gov.**

### To set up SFT:

1. Log on to the Health Commerce System
2. Click on **My Content** → **My Applications**
3. Click the letter '**S**' and select **Secure File Transfer 2.0**
4. Click on the green button with the white plus sign to add it to your My Applications list.
5. Once added, click on Secure File Transfer 2.0 from your My Applications list to open.
6. Under "Register (only once)" Click the yellow button that says "Launch the Secure File Transfer 2.0"

### I want to...

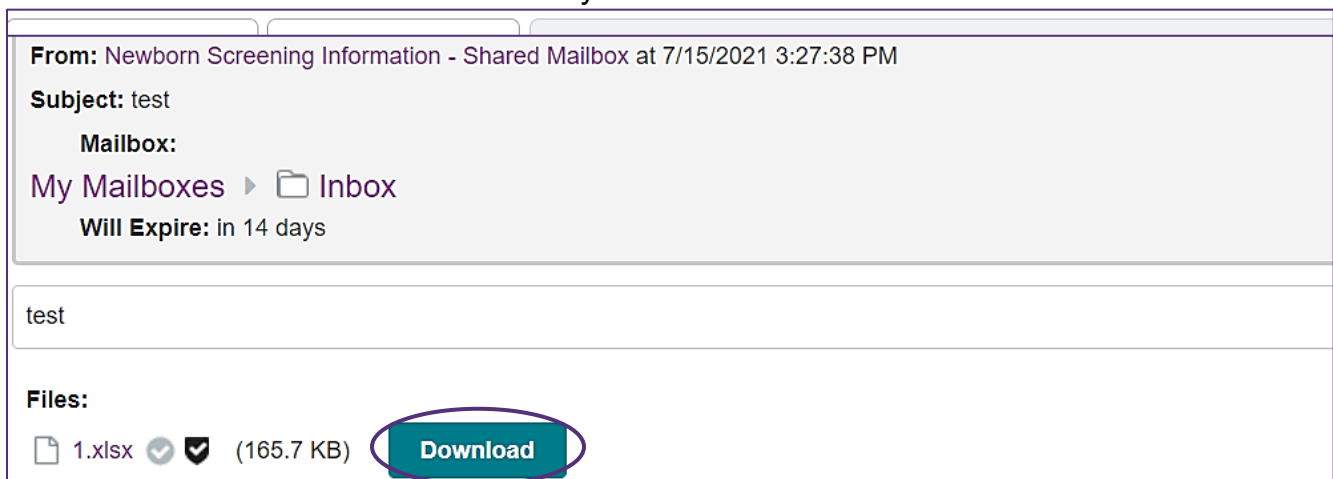
#### Register (only once)

- Click the **Launch the Secure File Transfer 2.0** button. By clicking the button, the utility recognizes you as a user.

7. You will be redirected to the SFT 2.0 home page. You are now registered and can begin receiving documents from the NBSP.

### To open a package using SFT:

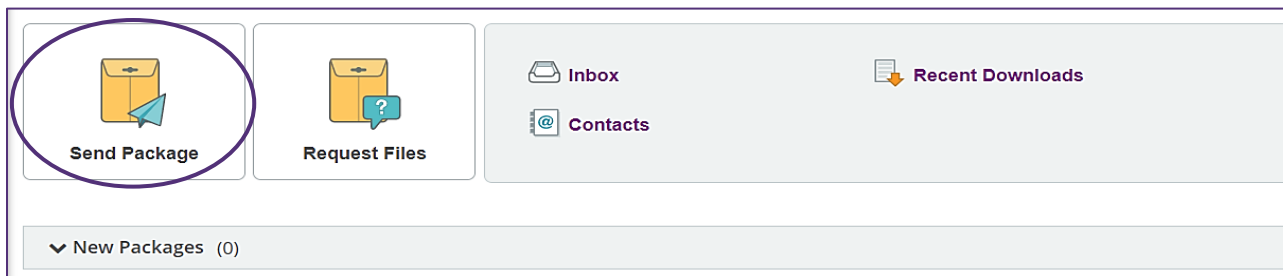
1. You will receive an email notification after a package has been sent to you.
2. Open the SFT 2.0
3. New packages notifications will appear on your home page.
4. To open the package, open your inbox and click on the text in the Subject field of the package.
5. Click "Download" to view and save any attached files.



### To send a package using SFT:

1. Open the SFT 2.0
2. Click "Launch the Secure File Transfer 2.0" button at the top of the page

## 3. From the home page, click Send Package



4. Click in the 'To' field and enter the recipient's last name or Health Commerce System user ID. If you are sending to multiple recipients, use a comma or semi-colon in between names or IDs. (To send to the NBSP, type **Newborn Screening Information – Shared Mailbox** in the 'To' field).
5. Click the Check Recipients button.
  - a. If there are multiple people with the same last name, a list will come up and you can put

- a check mark next to the correct name.
  - b. If entered the Health Commerce System ID, the user information should auto populate into the 'To' field.
6. Enter a Subject and a Note.
7. Click Upload File to add a file.
  - a. Browse to file location and select file
  - b. Click Upload
8. Click the Delivery Receipt(s) box if you want to be notified when the recipient opens the SFT message you have sent them, then click send.

## CEO Letters

9. Per [Section 69-1.3\(f\)\(1\) of the Title 10 of the New York Codes, Rules and Regulations](#), “when notified by the testing laboratory that a repeat specimen is required, the hospital shall notify the parent(s) and responsible provider within one (1) business day that a repeat specimen is required from the newborn. The hospital shall collect the repeat specimen, pursuant to guidance issued by the testing laboratory, and submit it to the testing laboratory as soon as practicable”.
10. When the NBSC at a hospital does not fulfill his/her follow-up duties **within 90 days** of the newborn screening result being issued, a letter detailing the non-compliance is sent to the hospital's CEO. Any hospital that receives one or more CEO letters is required to submit written policies and procedures related to the collection, storage, tracking and shipping of specimens and documentation of completion of annual training for the employee who collected the specimen **within 30 days** of the letter date.
11. If you have contacted the parent(s) and responsible provider of the infant to inform them of the needed repeat and have submitted documentation of that contact to the NBSP **within 90 days** of the results being released, a CEO letter will not be issued. However, if no repeat specimen is received and we do not receive notice of the NBSC's follow-up efforts, a CEO letter may be issued.

## Section 8: Hospital Performance Data

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### Hospital Report Cards

Each month, your hospital will receive a monthly report card that details your compliance in the following areas:

1. **Specimens Collected Within 36 Hours of Age** (initial specimens only)
2. **Specimens Received at Lab Within 48 Hours of Collection**
3. **Unsuitable Specimens**: Specimens submitted that were unsuitable for testing
4. **Unsuitable Specimens (Non-NICU)**: Non-NICU specimens submitted that were unsuitable for testing
5. **Incomplete Blood Collection Form (Missing Data)**: Blood collection forms submitted with missing and/or incorrect required data fields. Required data fields are as follows:
  - Date of Birth
  - Time of Birth (military time)
  - Date of Specimen
  - Time of Collection (military time)
  - Birth Weight (grams)
  - Gestational Age (weeks/days)
  - Sex
  - Birth Order
  - Medical Record Number
  - Zip Code (under mother's address)
  - Mother's Date of Birth

The report cards also show your hospital's rank among all birth hospitals in NYS. The report cards are emailed each month to the following designees at each hospital:

1. CEO
2. Newborn Screening Coordinator
3. Director of Nursing
4. Nurse Manager, Nursery
5. Nurse Manager, NICU
6. Quality Assurance/Risk Manager
7. Physician Receiving Abnormal Results

Your hospital's newborn screening team should review each monthly report card. If your hospital's report card shows areas of low compliance, process improvements should be made. Process improvements may include, but are not limited to:

- Updating written protocols for specimen collection
- Implementing additional education for staff
- Improving/updating staff training protocols
- Reviewing the New York State newborn screening regulation

## Site Visits

If your hospital report cards show areas of low compliance, and you aren't sure how to improve, please email [nbsinfo@health.ny.gov](mailto:nbsinfo@health.ny.gov) to request a virtual site visit.

A virtual site visit is a meeting between NBSP staff and your hospital's key newborn screening team members to outline your hospital's strengths and weaknesses regarding newborn screening, and to discuss quality improvement efforts that may work well for your hospital. During a site visit you can expect:

- A presentation on key newborn screening regulations
- A visual of your hospital's newborn screening compliance over the last 18 months
- A discussion about your hospital's strengths and weaknesses
- Tailored suggestions for improvement
- Ample time to ask the NBSP team questions

Generally, a site visit takes about 2 hours to complete. Site visits are an excellent opportunity to strengthen your hospital's relationship with the NBSP and have open discussion about how to tackle barriers that prevent your hospital from making newborn screening improvements.

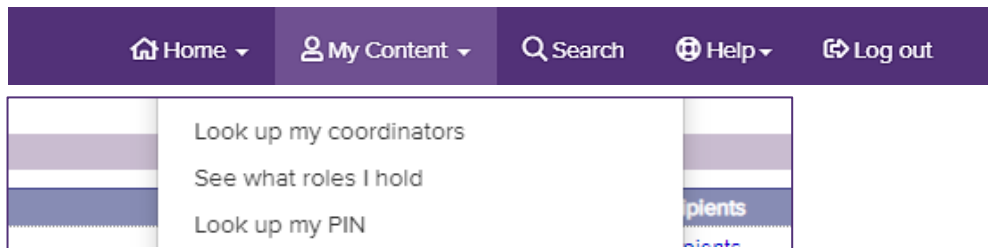


## Section 9: The Hospital Communication Portal

The Newborn Screening Program has launched an exciting new resource called the Hospital Communication Portal (HCP). The HCP is available through the Health Commerce System, and will allow you to view data, track specimens, respond to CEO letters, and more!

Follow the steps below to gain access to the HCP:

1. Log in to your HCS account. Click on **My Content** and then **See what roles I hold**.



2. If you hold the role of **Newborn Screening Hospital Communication App User**, go to step 6.
3. If you do **not** hold the role of **Newborn Screening Hospital Communication App User** click on **My Content** and then **Look up my coordinators**.
  - a. Contact any of the HCS Coordinators listed and ask them to assign you the role of **Newborn Screening Hospital Communication App User**.
4. If your HCS Coordinator does not know how to assign a role, they should follow these steps:
  - a. Click **Coordinator's Update Tool**.
  - b. Select the appropriate organization.
  - c. Click **Manage Role Assignments** (blue tab).
  - d. Click the **Modify** link located to the right of the role name.
  - e. Under section 2 (if no one is in the role) or section 3 (if the role has been assigned), **check the box to the right of the person** with the ID you wish to add to the role.
  - f. Avoid assigning the role if you see an **NA** after a user's name. This will not assign the user any permissions.
  - g. If you cannot locate the person on the list, then proceed to the last option, **Search for Person(s) by Name**:
    - i. Enter the last name in **Search for Person(s) by Name** and click **Submit**.
    - ii. Select the person in the list with a valid user ID.
    - iii. Click **Add Role Assignments**.
    - iv. Assign the appropriate user the role of **Newborn Screening Hospital Communication App User**.

**For additional assistance with HCS accounts and role assignment, please call the Commerce Accounts Management Unit (CAMU) at 866-529-1890 and press option 2.**

1. Once you have the proper role added, log in to your HCS account.
2. Look for the application in your **My Applications** list. The name of the application is **NBSHCA**.
  - a. If you do not see the portal, click on **My Content** and **All Applications**. Click **N** and add **Newborn Screening Hospital Portal** to your applications list by clicking the green plus sign **+** to the right of the application name.

A link to a comprehensive user guide is available on the home page of the HCP. The user guide provides step-by-step instructions for navigating and using the modules within the HCP.

## Section 10: Updating Newborn Screening Designees in HERDS

### Health Electronic Response Data System (HERDS)

All newborn screening contacts must be updated in an online application called the Health Electronic Response Data System (HERDS), available through the Health Commerce System. The Newborn Screening Hospital Contacts and Designee form must be completed **annually** and must be **updated within 30 days of a change** in designee. This form can only be accessed in HERDS and cannot be accessed through the Newborn Screening Application.

#### Accessing the HERDS Application

1. Log on to the Health Commerce System
  - If you cannot remember your user id or password, please call Commerce Accounts Management Unit at 1-866-529-1890.
2. Add the HERDS application, if you have not done so already.
  - a. Select **My Content** > **All Applications** from the Main Menu Bar.
  - b. Select **H** for HERDS
  - c. Click the **green button** with the white addition sign located to the right of the application name to add HERDS to your **My Applications** list.
  - d. Once added, click HERDS on the **My Applications** list to open.

#### Viewing and Completing the Form in HERDS

1. Click Data Entry.
2. Select the Newborn Screening Hospital and Contacts Designee form from the activity drop down box.
3. Complete and save the form. **NOTE: Completing/saving the form is NOT the final step in the process.**
4. The hospital CEO/President must log in to HERDS to review and submit the form. Since the hospital CEO is responsible for assigning designees, the form can only be submitted by the CEO/President user role.
5. If there are changes throughout the year, follow the same process but update only the changed information.

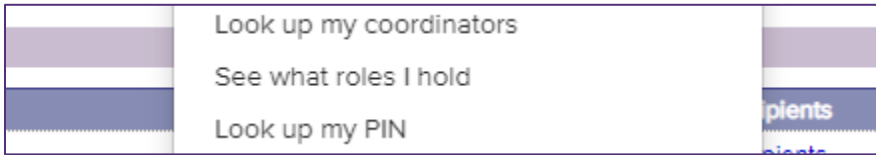
#### Assigning A Role in The Communications Directory

The form can be viewed/completed by the following roles:

- HERDS System Administrator
- CEO/President
- Chief of Neonatology/Newborn Services
- Director of Maternity Services
- Director of Nursing
- Newborn Screening Manager
- SDF Reporter

If you cannot see or complete the form, it is likely that you have not been assigned one of the above roles. You can check your assigned roles by clicking **My Content** on the purple bar at the top of the Health Commerce System homepage and then **See what roles I hold**.





The Health Commerce System Coordinator at each hospital can assign roles, if needed. To find the name of the Health Commerce System Coordinator at your institution, Select **My Content >Look up my coordinators**.

The Health Commerce System Coordinator at your hospital can assign roles by following the directions below:

1. Click **Coordinator's Update Tool**
  - Select the appropriate organization
  - Click **Manage Role Assignments** (blue tab) Click the **Modify** link located to right of the role name
  - Under section 2 (if no one is currently in role) or section 3 (if role has been assigned), **check the box to the right of the person** with an ID you wish to add to the role.
2. Avoid assigning the role if you see an **NA** after a user's name. This will not assign user any permissions.
3. If you cannot locate the person on the list, then proceed to the last option, **Search for Person(s) by Name**.
4. Enter the person's last name in the **Search for Person(s) by Name**.
5. Click **Submit**
6. Select the person in the list with a valid user ID
7. Click **Add Role Assignments**.

If the person and user ID appear in Manage People, you can use this method to assign one or more roles:

3. Click **Coordinator's Update Tool**
  - Select the appropriate organization
  - Click **Manage People** (blue tab)
  - Click on the user's name you want to assign role(s) to
    - a. If you do not see the user in the list, the user may have a Primary Organization with another facility/agency or may have attained a Health Commerce System account using their medical license. In other words, you will not see the user in your Manage People tab. Use instructions above.
4. Click **Manage Role Assignments** tab
5. Check the box next to the role(s) you wish the user to hold
6. Click **Revise Role Assignments**.

For additional assistance, please call the Commerce Accounts Management Unit (CAMU) at 866-529-1890 press option 2. The NBSP cannot complete these steps on your behalf.

## Newborn Screening Designee Descriptions

The following provides descriptions of titles identified in the Newborn Screening Hospital Contacts and Designee form and the responsibilities for each role:

### Chief Executive Officer

- Is aware of and fully understands their newborn screening responsibilities as outlined in 10 NYCRR 69-1.3 (access the regulation [here](#)).
- Ensures that all duties are appointed to appropriate hospital personnel who will act on their behalf to carry out those duties.
- Informs appointed designees and contacts of their roles and responsibilities.
- Reviews and submits the Newborn Screening Hospital Contacts and Designee form annually and within 30 days of any designee changes.

### Newborn Screening Coordinator (NBSC)

- Ensures that the hospital has received newborn screening results on all infants.
- Resolves discrepancies related to specimen identification, provides missing or illegible data submitted with the specimen and/or provides follow-up information.
- Documents the infant's LAB ID in the discharge summary.
- Receives unsuitable/sub-optimal specimen reports from the NBSP.
- Ensures that repeat specimens are submitted after an unsuitable/sub-optimal specimen or when a borderline newborn screening result is issued.
- Contacts the infant's post discharge PCP for notification of the need for a repeat specimen.
- Documents all efforts made to secure a repeat specimen within 90 days of receipt of the abnormal result if a repeat specimen cannot be obtained.
- Orders, receives, properly stores, and distributes the newborn blood collection forms and newborn screening educational materials.
- Communicates with the Department of Health as necessary regarding maternal/newborn HIV testing regulations in the labor, delivery, and nursery settings.

### Quality Assurance/Risk Manager

- Monitors quality indicators as provided in the Monthly Report Card.
- Remediate institutional performance issues.
- Conducts/ensures staff receives education related to newborn screening.
- Documents completion of training for all staff involved in the newborn screening process.

### Director of Nursing

- Assumes the responsibilities of the quality assurance/risk manager in their absence.

### Nurse Manager, Nursery

- Provides information, resolves problems, and performs other duties related to NBS. If NBSC is unavailable, the nurse manager will perform duties involving infants under hospital's care at the time of specimen submission.

### Nurse Manager, NICU

- Provides information, resolves problems, and performs other duties related to NBS. If NBSC is unavailable, the nurse manager will perform duties involving infants under hospital's care at the time of specimen submission.

**Physician Receiving Abnormal Results**

- Receives all abnormal test results and takes appropriate action to ensure newborns receive appropriate follow-up. May delegate the receipt of the abnormal test results to the NBSC.

**HIV Physician Designee**

- Receives all abnormal HIV test results and takes appropriate action to ensure newborns receive appropriate follow-up. Resolves discrepancies related to individual HIV box entries. May delegate this responsibility.

**Specimen Packaging and Shipping Issues Contact**

- Prepares the specimens for UPS pickup and transport to the NBSP.
- Ensures that transport forms are complete.
- Serves as a contact for any shipping issues.

## Section 11: Overview of the Newborn Screening Program Website

Much of the information in this toolkit can also be found on the NBSP's website, which has the most up to date information regarding newborn screening protocols, laws and regulations, and information for families and healthcare providers. It is an important resource for all newborn screening stakeholders.

Please visit our website regularly for important program updates:

<https://www.wadsworth.org/programs/newborn/screening>



Home » Public Health Programs » Newborn Screening and Genetics » Newborn Screening Program

Newborn screening refers to medical tests, the majority of which are genetic, performed to identify babies with certain disorders, which without intervention, may permanently impact newborns and their families. Early recognition and treatment of most of these disorders leads to a better outcome for the newborn. The Newborn Screening Program's goal is to help affected babies live as long and normal of a life as possible.

The Newborn Screening Program effectively identifies babies with certain disorders and is required for all newborns born in New York State unless the parents confirm, in writing, that they have a religious objection.

Quick Facts about Newborn Screening:

- A small blood sample is collected by pricking your newborn's heel usually 1-2 days after birth.
- The blood is used to screen for 50 different disorders.
- There is no charge to you for this service.
- Most newborns will not have one of these disorders.
- Newborns with one of these disorders may look healthy at birth, which is why the testing must be performed to find those with a disorder. The earlier treatment is started, the better the outcome is for your newborn.
- Screening is designed to identify all newborns with the potential for one of these disorders. Further testing is then required to verify whether or not your newborn has the disorder.

We work closely with health care providers to ensure newborns with abnormal test results receive appropriate confirmatory diagnoses and treatment.

No test is perfect. If your newborn's healthcare provider suspects there is a problem or your newborn does not seem right despite a normal newborn screening result, your newborn may need further testing.

CLIA # 33D2005937 | PFI # 8523

**Program Updates**

**Newborn Screening and Genetics**

Newborn Screening Program

Screened Disorders

Information for Families

Information for Healthcare Providers

Specialty Care Centers

Laws & Regulations

Funding

Selected Publications

History

Cancer Referrals

Pediatric Referrals

When you visit the website, you will see a purple navigation pane on the right-hand side of the home screen. There are different topic headings listed on the navigation pane. Please take time to click through each heading and review the information stored there.

Though you should explore the entire website, the **Information for Healthcare Providers** and **Laws & Regulations** headings will be the most applicable to NBSCs. The following pages of the toolkit will outline what you can expect to find under those headings, and where our most helpful information for NBSCs is stored.



## Information for Healthcare Providers

Overview of Laboratory Testing	A description of the specimen testing procedure, from receipt of specimens at the lab to reporting results
Specimen Collection	<ul style="list-style-type: none"> <li>• Proper specimen collection techniques</li> <li>• How to avoid unsuitable specimens</li> <li>• A video tutorial for proper specimen collection</li> </ul>
Obtaining Results	<ul style="list-style-type: none"> <li>• A link to the Secure Remote Viewer (to access results)</li> <li>• A link to the Record Request form (for out of state providers and screens collected before 2011)</li> </ul>
Forms	A link to general newborn screening forms, such as follow-up summary forms, transit forms, and diagnostic forms for various disorders
Requesting Newborn Screening Materials	A fillable form to request newborn screening materials including blood collection forms, For Your Baby's Health brochures (in multiple languages), and various posters
Hospital Contacts and Designees	Instructions to access HERDS and update hospital designees
Notes for Hospitals	Archived notes from monthly hospital report cards

## Laws & Regulations

The NBSP was established in Public Health Law (2500a; 2500f) in 1965 and is described by regulations (NYCRR 10, subpart 69-1) that are updated regularly to maintain the timeliness and efficiency of the NBSP. It is important to understand these laws and regulations when acting as the NBSC for your hospital.

Newborn Screening regulations were most recently updated in February 2019. These updates led to changes in how birth hospitals collect, dry, and ship newborn screening specimens. In response to the regulation updates, the NBSP conducted a series of six webinars that explained all changes in-depth.

Watching the webinars is a great way to become familiar with the newborn screening regulation and provides a great overview of hospital responsibilities regarding newborn screening.

## Helpful Web Addresses

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There are many links embedded in the toolkit. Below is a list of the pages that have embedded links and the full web address that corresponds to each embedded link.

### Page 4:

- Newborn Screening Regulations: <https://regs.health.ny.gov/volume-1a-title-10/content/subpart-69-1-newborn-screening-phenylketonuria-and-other-diseases>

### Page 5:

- Register for a Health Commerce System account (prescribing medical professionals): <https://apps.health.ny.gov/pub/top.html>
- Register for a Health Commerce System account (other users): <https://apps.health.ny.gov/pub/usertop.html>
- Health Commerce System Log in: <https://hcsauth.health.ny.gov/hcsauthenticationendpoint/login.do?RelayState=%2Fhcs%2Findex.html&commonAuthCalleePath=%2Fsamlso&forceAuth=true&passiveAuth=false&tenantDomain=carbon.super&sessionDataKey=c68f34e2-df7a-40c7-8265-b55504709ea1&relyingParty=hcs&type=samlso&sp=hcs&isSaaSApp=false&authenticators=BasicInternalCustomAuthenticator%3ALOCAL>

### Page 6:

- Order Newborn Screening Materials: <https://www.wadsworth.org/programs/newborn/screening/providers/request-materials>

### Page 7:

- Order Newborn Screening Materials: <https://www.wadsworth.org/programs/newborn/screening/providers/request-materials>

### Page 9:

- Information on Specimen Collection: <https://www.wadsworth.org/programs/newborn/screening/providers/specimen-collection>

### Page 12:

- Specimen Collection Video Guide: <https://www.wadsworth.org/programs/newborn/screening/providers/specimen-collection>

### Page 14:

- Refusal of Newborn Screening Form: [https://www.wadsworth.org/sites/default/files/WebDoc/1698495387/refuse\\_newborn\\_screening.pdf](https://www.wadsworth.org/sites/default/files/WebDoc/1698495387/refuse_newborn_screening.pdf)

### Page 15:

- Newborn Screening Transport Form: [https://www.wadsworth.org/sites/default/files/WebDoc/1539761599/Newborn\\_Screening\\_Transport\\_Form.pdf](https://www.wadsworth.org/sites/default/files/WebDoc/1539761599/Newborn_Screening_Transport_Form.pdf)
- UPS Website: [https://www.ups.com/track?loc=en\\_US&requester=ST/](https://www.ups.com/track?loc=en_US&requester=ST/)

### Page 16:

- Record Request Form: [https://www.wadsworth.org/sites/default/files/WebDoc/POL\\_5.6%20v2.3%20Request%20for%20Newborn%20Screening%20Results%20and%20Physician%20Attestation%20Statement.pdf](https://www.wadsworth.org/sites/default/files/WebDoc/POL_5.6%20v2.3%20Request%20for%20Newborn%20Screening%20Results%20and%20Physician%20Attestation%20Statement.pdf)

### Page 24:

- Follow-up Summary Form: [https://www.wadsworth.org/sites/default/files/WebDoc/1334337137/Follow-Up\\_Summary\\_Form.pdf](https://www.wadsworth.org/sites/default/files/WebDoc/1334337137/Follow-Up_Summary_Form.pdf)

### Page 29:

- Regulation Describing the Duties of a Hospital CEO: <https://regs.health.ny.gov/content/section-69-13-responsibilities-chief-executive-officer>

### Page 32:

- Regulation Describing the Duties of a Hospital CEO: <https://regs.health.ny.gov/content/section-69-13-responsibilities-chief-executive-officer>

### Page 36:

- Newborn Screening Program Website: <https://www.wadsworth.org/programs/newborn/screening>



## Glossary of Newborn Screening Terms

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1. **Confirmatory/diagnostic/independent test** – a clinical test (blood work, urine test, imaging study, etc.) to confirm or rule out the presence of a specific disease suggested because of a positive screen.
2. **Documentation** – faxes, letters or emails received by the NBSP that provide updates or new information on cases. Examples include follow-up summary forms returned by provider or hospital, emails from parents to provide correct pediatrician, undeliverable mail returned by the Post Office, and independent lab results.
3. **Follow-up** – timely actions taken to ensure a newborn with positive results receives appropriate repeat screening, diagnostic work-up, and/or evaluation.
4. **Hospital of birth (HOB)** – hospital where a baby was born.
5. **Independent testing** – a clinical test, usually blood work, ordered by a clinician to follow-up on a specific newborn screen result. Examples include thyroid function testing for borderline TSH results, and plasma amino acids for borderline amino acid disorders.
6. **Indeterminate screen** – a newborn screen for which the testing failed for one or more disorders and a result is not available. A repeat screen or independent testing is recommended following an indeterminate screen.
7. **Long-term follow-up (LTFU)** – assessment of the clinical outcome after a disease is confirmed.
8. **Lost to follow-up** – newborn is unable to be located for completion of follow-up.
9. **Mailer** – test report; a term used internally within the NBSP, but it is also used on the Secure Remote Viewer on the newborn screening application on the Health Commerce System website.
10. **Newborn Screening Coordinator (NBSC)** – a hospital staff member assigned by the institution's CEO to be a point person for the NBSP. Their responsibilities include working to obtain repeat newborn screens as directed by the NBSP and communicating these efforts to NBSP staff.
11. **Notebook** – written notes in the Laboratory Information Management System documenting phone calls, reviewed or sent correspondence, and/or any other case updates. Notebooks may be entered and read by NBSP staff as well as by hospital staff using iCMS.
12. **Pilot study** – a research study to detect one or more disorders that are not on the regular newborn screening panel. Pilot studies are usually small (limited to just a few hospitals) and require consent, meaning that the parents are offered the study and can choose whether they want to participate.
13. **Presumptive positive/borderline** – Newborn screening result is outside of the normal range but not at the referral level; a repeat screen or independent testing is required.
14. **Primary Care Provider (PCP)** – the newborn's pediatrician, neonatologist, or medical provider responsible for the baby's care.
15. **Referral** – the result of the screen is clearly abnormal, above the referral cut-off, and requires independent testing and/or evaluation with a specialist. Referrals are identified and provided to NBSP follow-up staff by NBSP Laboratory staff.
16. **Repeat** – an additional newborn screen requested following a borderline, indeterminate or unsuitable screen.
17. **Secure File Transfer** – an application on the Health Commerce System website that can be used to send files securely between two Health Commerce System users.
18. **Specialist** – a medical provider with clinical expertise in the condition the baby screened positive for.
19. **Sub-optimal screen** – a newborn screen that is poor in quality but still tested, although the quality of the result is unclear. Examples include specimens that are clotted or that exhibit serum rings.
20. **Unsuitable specimen** – a newborn screen that is so poor in quality that it is untestable. Examples include specimens that lack sufficient quantity to do the testing and specimens that are diluted, contaminated, or discolored.

## Glossary of Newborn Screening Abbreviations and Acronyms

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1. **AKA** – also known as
2. **B/B; B/G** – baby boy, baby girl
3. **CAIN06, CAPT10, etc.** – all codes to describe calls made to the hospital or provider
4. **CB** – call back
5. **DOB** – date of birth
6. **DOC** – date of specimen collection
7. **DOS** – date of specimen
8. **DX** – diagnosis
9. **EDT** – electronic data transfer
10. **Endo** – endocrine
11. **FU or F/U** – follow-up
12. **HOB** – hospital of birth
13. **IMDWCM** – disease category/hospital – specialty care centers
14. **IRT** – immunoreactive trypsinogen
15. **LAB ID** – laboratory identification number
16. **LEIN10, LEPT10, LEIP73, etc.** – all codes to describe letters mailed to hospitals and providers
17. **LEPA80, LEPA85, etc.** – all codes to describe letters mailed to the infant’s parents
18. **LM** – left message
19. **LMOVM** – left message on voicemail
20. **MCH** – maternal child health
21. **MCH 3** – blood collection form, also called filter papers or DOH-1514
22. **NBS** – newborn screening
23. **NBSP** – newborn screening program
24. **NICU** – neonatal intensive care unit
25. **NP** – nurse practitioner
26. **PA** – physician’s assistant
27. **PC** – phone call
28. **PCP** – primary care provider
29. **PCR** – polymerase chain reaction
30. **Ped** – pediatrician
31. **RDE** – remote demographic entry
32. **Rec’d** – received
33. **REF** – referral
34. **RTS** – return to sender
35. **S/W** – spoke with
36. **SCC** – specialty care center
37. **SFT** – secure file transfer
38. **SN** – screen negative
39. **TFT** – thyroid function test
40. **THA2, PP, DOB, REF, etc.** – all mnemonics to describe test results
41. **THY** – thyroid
42. **TOB** – time of birth
43. **TOC** – time of specimen collection
44. **TPN** – Total parenteral nutrition
45. **TSH** – thyroid stimulating hormone
46. **UNS** – unsatisfactory specimen
47. **VM** – voice mail
48. **WAL** – within acceptable limits; normal newborn screening result

## Resources

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The following pages include several resources and educational tools that you may find helpful as an NBSC. The forms located on the following pages can also be found on the NBSP website.

**NEWBORN SCREENING PROGRAM**  
**New York State Department of Health**  
**Wadsworth Center, David Axelrod Institute**  
**120 New Scotland Avenue Albany, NY 12208**  
**Phone: (518) 473-7552 Fax: (518) 474-0405**

## Follow-Up Summary Form

Dear Health Care Provider:

We have not yet received a repeat specimen for this newborn. Documentation of your follow-up activities is required, as specified in section 69-1 of Title 10 of the official compilation of Codes, Rules & Regulations of the State of New York. In lieu of filling out this form, updates may be provided in the Case Demographics module in the Newborn Screening application on the Health Commerce System website. **Please summarize your efforts to obtain a repeat specimen.**

**NEWBORN INFORMATION:**

Name at Time of Birth: \_\_\_\_\_

Other Names (AKA): \_\_\_\_\_

Single Birth  Twin A  Twin B  Other \_\_\_\_\_

Mother's Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Sex: Male  Female

Hospital of Birth: \_\_\_\_\_

Medical Record Number: \_\_\_\_\_

**Status:**

In-patient at this facility

Transferred to another facility, specify \_\_\_\_\_

Discharged to home

**Calls to parent:**

Dates called: \_\_\_\_\_

\_\_\_\_\_

**Letters to parent:**

Dates sent: \_\_\_\_\_

\_\_\_\_\_

**Calls to primary care provider:**

Dates called: \_\_\_\_\_

\_\_\_\_\_

**Letters to primary care provider:**

Dates sent: \_\_\_\_\_

\_\_\_\_\_

**Comments:** \_\_\_\_\_

\_\_\_\_\_

We appreciate your efforts to obtain a repeat specimen. Thank you for your cooperation. Sincerely,



Michele Caggana, SC.D., FACMG  
 Director, Newborn Screening Prog



Department of Health

KATHY HOCHUL  
Governor

MARY T. BASSETT, M.D., M.P.H.  
Commissioner

KRISTIN M. PROUD  
Acting Executive Deputy Commissioner

### Request for Newborn Screening Results & Physician Attestation Statement

Child's Name: \_\_\_\_\_

Child's Date of Birth: \_\_\_\_\_

Child's Hospital of Birth: \_\_\_\_\_

Child's Sex:  Male  Female

Medical Record Number from the Hospital of Birth: \_\_\_\_\_

AKA (Aliases): \_\_\_\_\_

Mother's Name: \_\_\_\_\_

Reason for Request:  NCAA  OTHER

I, the undersigned physician of the above identified individual, certify that the following are true:

- A. I am requesting the Newborn Screening results as the physician of record who is providing medical care for this individual.
- B. I understand that per Part 58-1 of the New York Codes, Rules and Regulations (NYCRR) Title 10, Clinical Laboratories, Section 58-1.8 results are to be used in the conduct of my medical practice or in the fulfillment of my official duties.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

Printed Name: \_\_\_\_\_

Medical License Number: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Phone Number: \_\_\_\_\_

Fax Number: \_\_\_\_\_

*Please fax the completed form to the Newborn Screening Program at (518) 474-0405.*

## Hospital Self-Evaluation Form for Newborn Screening Protocol

Hospital: \_\_\_\_\_ Date: \_\_\_\_\_

Evaluation Completed By: \_\_\_\_\_  
Name and Title

### Newborn Screening Policy

Does your unit have a written NBS policy?  Yes  No

If yes, does it comply with New York State NBS regulations?  Yes  No

NYS NBS Policy Review	Addressed/Part of Nursing Protocol	Not Addressed
Definition of NBS		
Training of Staff involved with NBS		
Specimen Collection <i>Proper collection protocols, how to prep for shipment, etc.</i>		
Specimen Collection Protocol for NICU Babies <i>When to collect, how many specimens to collect, protocol for transferred babies, etc.</i>		
Parental Refusals <i>Parental education, filling out refusal forms, sending completed forms to the NBS Program</i>		
Properly Filling out the Blood Collection Form or RDE		
NBS Demographic Correction Procedures		
Collection Log Requirements		
NBS Follow-up <i>Documenting results, sending results to PCPs, collecting and scheduling repeats, etc.</i>		

NYS NBS Process Review
Do you have a system in place to ensure that every newborn is screened prior to discharge? <input type="checkbox"/> Yes <input type="checkbox"/> No
How often do you check the expiration dates on filter papers? <input type="checkbox"/> Other _____ <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Every _____ Weeks <input type="checkbox"/> Monthly <input type="checkbox"/> Every _____ Months <input type="checkbox"/> Yearly Who is responsible for checking expiration dates? _____
How are the filter papers ordered? _____ Who orders filter papers? _____ Where are extra filter papers stored? _____
How do you provide parent education materials? <input type="checkbox"/> Verbal Discussion <input type="checkbox"/> NBS Brochure(s) <input type="checkbox"/> Other: _____ Do you provide the NBS brochure in the mother's preferred language? <input type="checkbox"/> Yes <input type="checkbox"/> No Are parents advised to ask their baby's PCP for NBS results during their baby's first appointment? <input type="checkbox"/> Yes <input type="checkbox"/> No
Does your facility utilize the NBS Parental Refusal Form? <input type="checkbox"/> Yes <input type="checkbox"/> No Are parents' fears/questions addressed regarding NBS in the event of a refusal? <input type="checkbox"/> Yes <input type="checkbox"/> No
Is the demographic information on the blood collection form verified with parents at the time of collection? <input type="checkbox"/> Yes <input type="checkbox"/> No Are parents advised the importance of having a planned pediatrician? <input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have a designated area where blood collection forms are placed to dry? <input type="checkbox"/> Yes <input type="checkbox"/> No Are blood collection forms dried horizontally for at least 3 hours? <input type="checkbox"/> Yes <input type="checkbox"/> No Do you have measures in place to minimize the risk for contamination while filter papers are drying? (free of standing water, away from food and drink, away from direct sunlight, etc.) <input type="checkbox"/> Yes <input type="checkbox"/> No
Who checks on the drying status of filter papers? _____

**NYS NBS Process Review Cont.**

Do you have measures in place to ensure specimen date and time of collection are documented?  Yes  No

Who is responsible for checking NBS results? \_\_\_\_\_

Who records NBS results? \_\_\_\_\_

How are NBS results recorded?

Results are scanned into child's chart  Manually entered in child's chart  Recorded in a Logbook  Other

If other, please specify \_\_\_\_\_

**Newborn Screening Collection Log Review**

Does your unit maintain a Collection Log for specimens?  Yes  No

Collection Log Components	Yes	No	Collection Log Components	Yes	No
Infant's Name			LABID		
Date of Birth			Specimen Collection Date		
Time of Birth			Specimen Collection Time		
Medical Record Number			Collector Initials		
Attending Physician			Specimen Quality Reviewed		
Planned Pediatrician Upon Discharge			Demographics on Blood Collection Form or RDE Reviewed		
NICU Status			NBS Results		
TPN Status			Date NBS Results Received		

**Shipping and Tracking**

Do you maintain a courier/transit log?  Yes  No

Do you have a process to document when specimens are dropped off to be shipped?  Yes  No

Do you have a process to document when specimens are picked up?  Yes  No

Does your hospital use UPS or a private courier for specimen shipping? \_\_\_\_\_

What days of the week are specimens picked up at your facility (circle all that apply): **S M T W TH F S**

Location and time for specimen pick-up \_\_\_\_\_

Who is in charge of tracking specimens and testing results? \_\_\_\_\_

Do you have a process in place to ensure NBS specimens are NOT batched?  Yes  No

**Training**

Do you keep documentation of when staff training takes place?  Yes  No

Is refresher training provided to those who do not follow NBS guidelines?

(collect a late specimen, collect an unsatisfactory specimen, incorrectly document data, etc.)  Yes  No

How often are staff trained on NBS policy and process?

**Hospital Compliance**

Who is responsible for reviewing monthly hospital report cards? \_\_\_\_\_

Who is responsible for acting on the data presented in the hospital report cards? (improving collection times, lowering unsuitable rates and missing information, etc.) \_\_\_\_\_

Who is responsible for making sure designee information is up to date in HERDS/Health Commerce System? \_\_\_\_\_



## Fact Sheet: Newborn Screening Timeliness

### New York State Newborn Screening Program

# Timeliness for Newborn Screening



Department  
of Health

Wadsworth  
Center

## The Importance of Timeliness

The timely collecting, shipping, and reporting of screening results according to New York State regulations is extremely important for promoting good health outcomes in newborn babies. When the regulations for timely collection are not followed, it can lead to disastrous delays in diagnostic efforts and treatment by the infant's provider.

## From Birth to Lab: Optimal Newborn Screening



Baby born  
**Hour 0**



Specimen  
collected **24-36  
hours of life**



Specimen sent to  
the lab **within 24  
hours of  
collection**



Specimen  
received by the lab  
**within 48 hours  
of collection**

## COLLECTION IN THE NICU

### Admission

A specimen should be collected once an infant is admitted to the NICU, regardless of age

### 48-72 hrs

A second specimen should be collected between 48 and 72 hours of life

### 28 days

A third specimen should be collected at 28 days of life or discharge, whichever comes first\*

*\*A repeat screen may be requested sooner if the second screen has an abnormal result*

## The Newborn Screening Program's Goals for Reporting Results

For time-critical conditions, presumptive positive results are reported within 5 days of life.

**ALL newborn screening results are reported within 7 days of life.**

## Did you know?

Specimens should be air dried on a flat, nonabsorbent surface away from direct heat and sunlight for at least 3 hours prior to shipping.

## Fact Sheet: Requests for Repeats

New York State Newborn Screening Program

# Requests for Repeats



Department of Health

Wadsworth Center

## Reasons for a Repeat Request



### UNSUITABLE

Suboptimal for testing  
Quantity not sufficient for testing



### EARLY COLLECTION

Specimen collected before 24 hours of life



### DELAYED SPECIMEN

Specimen is received by the lab 14 or more days after collection



### BORDERLINE OR INDETERMINATE

A repeat specimen is needed to confirm or determine results

## Hospital Responsibilities

Check the Secure Remote Viewer regularly to determine when repeat screens are needed.

Notify the infant's parent(s) and provider within 1 business day of the results becoming available.

Be prepared to collect the repeat screen.

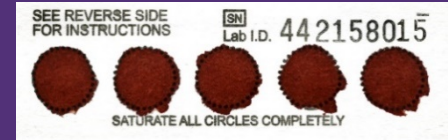
## Provider Responsibilities

Check each infant's results on the Secure Remote Viewer prior to the infant's first appointment.

Inform the infant's parent(s) of the results.

Collect the repeat screen if you are able or refer the family to the hospital of birth for a repeat.

## THE PERFECT SPECIMEN



- ✓ Is collected from an infant after the first 24 hours of life
- ✓ Has no foreign contaminants on the filter paper
- ✓ Has all printed circles completely filled with blood that is applied evenly on one side of the filter paper: free of layering and clots
- ✓ Is dried for at least three hours

For a full guide on collecting the perfect specimen, visit our [website](#)

## We're Here to Help

Are you having trouble reaching a family? Did they miss their appointment for a repeat? Let us know by phone, follow-up summary form, or iCMS.

To improve your unsuitable collection rate, visit our website or call the Newborn Screening Program for suggestions.

## Fact Sheet: CEO Letters

### New York State Newborn Screening Program

# Hospital CEO Letters



Department  
of Health

Wadsworth  
Center

## Overview

When a hospital does not successfully obtain a requested repeat specimen **and** does not submit documentation to the Newborn Screening Program to summarize their follow-up efforts, a CEO letter is issued for the hospital. The purpose of the letter is to inform the CEO of the hospital's failure to comply with current NYS regulations for newborn screening. There are different types of CEO letters, which can be identified by the code on the bottom of the letter. If your hospital receives a CEO letter, promptly submit the required documentation.

## Communication is Key

If a hospital updates the Newborn Screening Program with their efforts to obtain a repeat newborn screen, no CEO letter will be issued, even if a repeat newborn screen is not collected. The hospital can update the Newborn Screening Program through case notes in iCMS, completed follow-up summary forms, or phone calls.

## Types of CEO Letters

Letter code	LECEOA	LECEOB	LECEOC	LECEOG
<i>Letter issued when</i>	The initial specimen was unsuitable for testing. After 90 days no repeat screen was submitted, and no documentation of the hospital's follow-up efforts was received by the Newborn Screening Program.	The initial specimen was collection prior to 24 hours of life. After 90 days no repeat screen was submitted, and no documentation of the hospital's follow-up efforts was received by the Newborn Screening Program.	The initial specimen screening result was outside of the normal range. After 90 days no repeat screen was submitted, and no documentation of the hospital's follow-up efforts was received by the Newborn Screening Program.	The initial specimen was collected late at more than 120 hours of life. After 90 days no completed late collection follow-up form was received by the Newborn Screening Program.
<i>Hospital should send</i>	Written policies and procedures related to the collection, storage, tracking and shipping of specimens and documentation of completion of annual training for the employee who collected this specimen.	Written policies and procedures related to the tracking and disposition of test results.	Written policies and procedures related to the tracking and disposition of test results.	Written policies and procedures relates to the collection of specimens and documentation of completion of annual training for the employee who collected this specimen.
<i>Response due within</i>	30 days of letter date	30 days of letter date	30 days of letter date	30 days of letter date

## Fact Sheet: Preventing Missing Data

# New York State Newborn Screening Program Preventing Missing Data



Department of Health

Wadsworth Center

### The Importance of Complete and Correct Data

The Newborn Screening Program uses the information on blood collection forms to interpret disseminate results to the appropriate parties. It is important that each hospital check blood collection forms for completeness and accuracy prior to shipping, paying extra attention to all required and critical data fields.

### Critical Data Fields

Six data fields are considered especially critical to screening results. Failing to accurately complete one or more of the following fields will result in **missing data** on your hospital's newborn screening report card and will delay the results of the screen until the correct information is provided. This delay has the potential to deny newborns the full benefit of timely screening. Critical data fields are: **Date of Birth, Time of Birth, Date of Specimen, Time of Collection, Birth Weight, and Gestational Age.**

### Electronic Data Transmission (EDT)

Hospitals using electronic data transmission should review all entries prior to submission. Hospitals using HL7 should promptly respond to NACK reports regarding areas of incomplete data transmission.

### Required Data Fields

Although the **entire blood collection form** must be filled out prior to shipment, the following 11 "required" data fields must be filled in completely and correctly to avoid **missing data** on your hospital's newborn screening monthly report card:



Date of Birth



Time of Birth (military time)



Date of Specimen



Time of Collection (military time)



Birth Weight (grams)



Gestational Age (weeks/days)



Sex



Birth Order



Medical Record Number



Zip Code (Mother's address)



Mother's Date of Birth

### Location of Required Fields

The screenshot shows a newborn screening form with various fields. Yellow boxes highlight the following fields: Infant's Last Name, Infant's First Name, Sex (Male/Female), Single birth (Yes/No), Date of Birth (MM/DD/YYYY), Time of Birth (Military Time), Date of Specimen (MM/DD/YYYY), Time of Collection (Military Time), Infant's Medical Record #, Gestational Age (Weeks/Day), Birth Weight (Grams), Mother's Date of Birth (MM/DD/YYYY), Mother's Name and Address (Last, First, Address, Apt.#, Zip), Sex (Male/Female), Birth Order (A-F), Medical Record Number, Zip Code (Mother's address), and Mother's Date of Birth (MM/DD/YYYY).