

Newborn Screening

Oklahoma State Department of Health
Newborn Screening Program

Phone: (405) 426-8310

Toll Free: 1 (800) 766-2223

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NewbornScreen@health.ok.gov



Newborn Bloodspot Screening

- **Purpose**

- Newborn screening (NBS) is the practice of testing **every** newborn for harmful or potentially fatal disorders that are not otherwise apparent at birth.
- **Early detection** and **prompt treatment** can make the difference between healthy development or lifelong impairment and possible death.



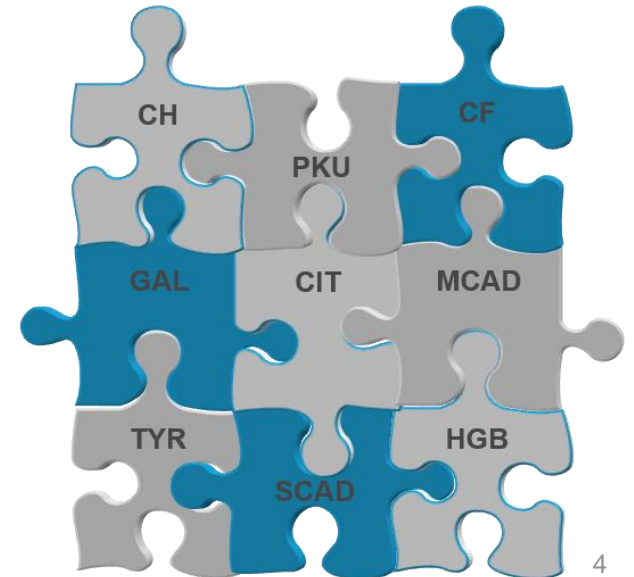
Screening vs. Diagnostic

- The newborn screen is just that... a *screen*.
 - Screening results, by themselves, **cannot** determine the presence or absence of a disorder.
- Diagnostic results refer to the combination of signs, symptoms, and test results that allows the doctor to **confirm** the diagnosis of a respective disease.



Who Decides?

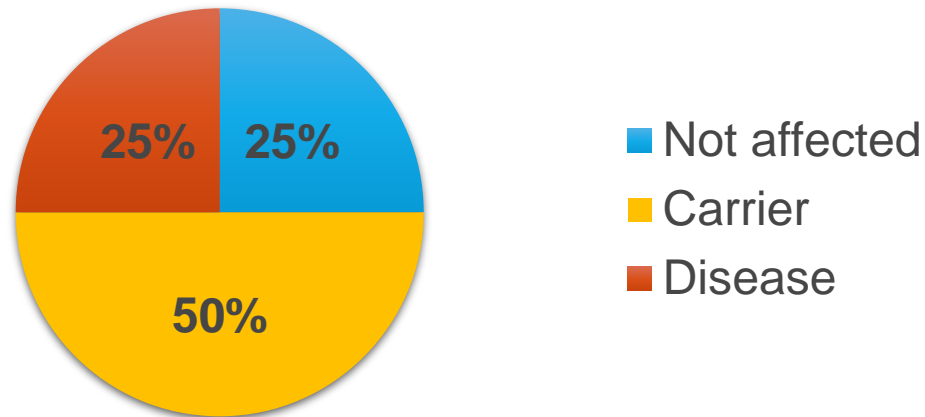
- In 2022 the Oklahoma legislature passed statute stating that the Oklahoma NBS panel will match the national recommended uniform screening panel (RUSP) to the extent practicable.
- Once a condition is added to the RUSP the NBS Program (lab and follow up) will determine practicability and readiness.
- Then the Infant and Children's Health Advisory Committee will provide recommendations to the Commissioner of Health to add the disorder.
- The Commissioner of Health will give final approval.
- Oklahoma currently screens for over 50 possible hidden disorders.
- Oklahoma will continue to expand.



Autosomal Recessive

- Most NBS disorders are autosomal recessive with the exception of:
 - Congenital Hypothyroidism (CH)
 - Some forms of Severe Combined Immunodeficiency (SCID)
 - X-Linked Adrenoleukodystrophy
- Usually no prior family history
- Risk for each pregnancy if both parents are a carrier of a disorder:

Possible Outcomes for Offspring of Parental Disease Carriers



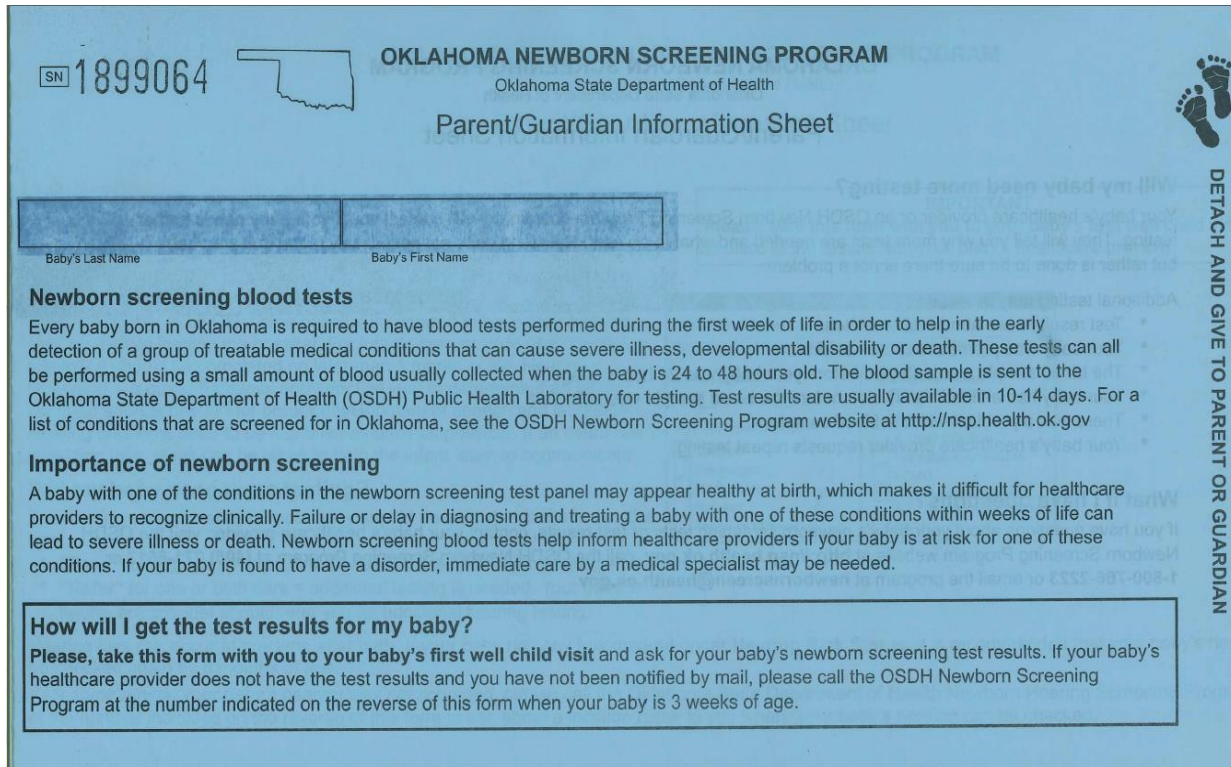
Parent Education



- NBS is collected on **every** baby born in Oklahoma.
- Importance of **correct** contact info & PCP for follow-up.
 - *No news is not good news!* Update NBS Program with changes in home address and/or PCP.
- Review hidden disorders, using NBS pamphlet as a guide.
- Specimens are kept by the OSDH lab for 42 days before being destroyed.
- Explain that most affected newborns do not exhibit signs & symptoms early on.
- Prompt identification & treatment of disorders is critical.



Parent Education

- Instruct parents to ask for screen results on first visit to PCP.
- Tell parents to bring the **Blue** or **Pink** slip to their baby's first doctor's visit.



SN 1899064  OKLAHOMA NEWBORN SCREENING PROGRAM
Oklahoma State Department of Health
Parent/Guardian Information Sheet 

Baby's Last Name _____ Baby's First Name _____

Newborn screening blood tests
Every baby born in Oklahoma is required to have blood tests performed during the first week of life in order to help in the early detection of a group of treatable medical conditions that can cause severe illness, developmental disability or death. These tests can all be performed using a small amount of blood usually collected when the baby is 24 to 48 hours old. The blood sample is sent to the Oklahoma State Department of Health (OSDH) Public Health Laboratory for testing. Test results are usually available in 10-14 days. For a list of conditions that are screened for in Oklahoma, see the OSDH Newborn Screening Program website at <http://nsp.health.ok.gov>

Importance of newborn screening
A baby with one of the conditions in the newborn screening test panel may appear healthy at birth, which makes it difficult for healthcare providers to recognize clinically. Failure or delay in diagnosing and treating a baby with one of these conditions within weeks of life can lead to severe illness or death. Newborn screening blood tests help inform healthcare providers if your baby is at risk for one of these conditions. If your baby is found to have a disorder, immediate care by a medical specialist may be needed.

How will I get the test results for my baby?
Please, take this form with you to your baby's first well child visit and ask for your baby's newborn screening test results. If your baby's healthcare provider does not have the test results and you have not been notified by mail, please call the OSDH Newborn Screening Program at the number indicated on the reverse of this form when your baby is 3 weeks of age.

DETACH AND GIVE TO PARENT OR GUARDIAN



Parent Education

- Review reasons why a repeat screen may be needed:
 - **Unsatisfactory Specimen**
 - **Out-of-range results**
 - Possible disorder identified
 - Hgb Trait condition
 - **Specimens collected less than 24 hours**
 - Risk for missing some disorders
 - **Premature or Sick Infants** (TPN & antibiotics could affect results)
 - **Not collected prior to a blood transfusion**



Filling out the Form

EXPIRATION DATE 2022-04-30
 Use black or blue ink ball point pen only. See full instructions for completion of form on back page.
 SN 1899064 ODH #450 REV 04, 2019

Oklahoma Newborn Screening (NBS) Form DO NOT WRITE HERE
 To order forms, call the OSDH NBS Program (405) 271-5070

<input type="checkbox"/> First Screen <input type="checkbox"/> Repeat Screen <input type="checkbox"/> Previous NBS Lab# _____		MEDICAL/FEEDING HISTORY (Check all that apply) <input type="checkbox"/> Transfusion Date ____ / ____ / ____ Time ____ : ____ (24 Hr Clock) <input type="checkbox"/> NICU/SCN <input type="checkbox"/> Lactose-Free Formula (Soy) <input type="checkbox"/> TPN/SNAP <input type="checkbox"/> Meconium Ileus <input type="checkbox"/> Lipids/Carnitine/MCT <input type="checkbox"/> Family History of CF	
Not Screened Due To <input type="checkbox"/> Refused <input type="checkbox"/> Expired ____ / ____ / ____ <input type="checkbox"/> Transferred ____ / ____ / ____ to _____		TESTS REQUESTED <input type="checkbox"/> HGB Only <input type="checkbox"/> GALT <input type="checkbox"/> Phe Monitor <input type="checkbox"/> CFTR	
BABY'S INFORMATION			
Last Name _____		First Name _____	
Birth Date ____ / ____ / ____ Time ____ : ____ (24 Hr Clock)		Sex <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	
Collection Date ____ / ____ / ____ Time ____ : ____ (24 Hr Clock)		Race (Check all that apply) <input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> American Indian <input type="checkbox"/> Pacific Islander	
Medical Record # _____	Gest. Age _____	Birth Wt. (gm) _____	Multiple Birth Order <input type="checkbox"/> A-H
MOTHER'S/GUARDIAN'S INFORMATION			
<input type="checkbox"/> DHS Custody <input type="checkbox"/> Adoption Last Name _____		First Name _____	
Address _____			Apt. # _____
City _____		State _____	Zip _____
Telephone # () - -		Alternate Telephone # () - -	
Mother's Date of Birth ____ / ____ / ____	Mother's Medicaid ID # _____	Mother's Last 4 of SSN _____	
PROVIDER'S INFORMATION			
Physician Ordering NBS (Last, First) _____			Provider ID# _____
Primary Care/Follow-up Physician (Last, First) _____			Provider ID # _____
PULSE OXIMETRY/CCHD SCREEN			
<input type="checkbox"/> Pass <input type="checkbox"/> Fail <input type="checkbox"/> Not Performed <input type="checkbox"/> Refused <input type="checkbox"/> Echo			
HEARING SCREEN			
Date of Final Screen ____ / ____ / ____ Right Ear: <input type="checkbox"/> Pass <input type="checkbox"/> Refer Left Ear: <input type="checkbox"/> Pass <input type="checkbox"/> Refer			
Screen Method <input type="checkbox"/> ABR <input type="checkbox"/> OAE		Hearing Risk Status (Select all that apply) <input type="checkbox"/> Family History <input type="checkbox"/> In Utero Infection <input type="checkbox"/> Craniofacial Anomalies <input type="checkbox"/> ECMO <input type="checkbox"/> Both Hyperbilirubinemia AND Exchange Transfusion <input type="checkbox"/> NICU	
If not screened, reason <input type="checkbox"/> Delayed <input type="checkbox"/> Discharged <input type="checkbox"/> No Supplies <input type="checkbox"/> Refused <input type="checkbox"/> Technical Problem			
SUBMITTER'S INFORMATION			
Submitting Facility's/Provider's ID # _____			
Submitter's Name/Address _____			

DETACH AND PLACE IN MEDICAL RECORD
 DETACH AND GIVE TO PARENT OR GUARDIAN
 DETACH AND GIVE TO PARENT OR GUARDIAN

Specimen testing will be delayed if the form is incomplete!



Filling out the Form

Specimen testing will be delayed if the form is incomplete!

- **Check expiration date**

- If the filter paper is expired, discard the paper, and check the stock of filter paper kits and discard all expired kits.
- Collect the specimen on a kit that is not expired.



Filling out the Form: Specimen Information

Specimen testing will be delayed if the form is incomplete!

- If this is the first specimen collected for the baby, check the “First Screen” box.
- If baby has had a previous screen, check the “Repeat Screen” box.
 - List the previous OSDH Lab Number, if applicable.



Filling out the Form: Specimen Information

Specimen testing will be delayed if the form is incomplete!

The image shows a full Oklahoma Newborn Screening (NBS) form. A red circle highlights the 'Expired' checkbox in the 'Not Screened Due To' section. A black arrow points from this circle to the zoomed-in view of the form below.

- If baby expires before a screen can be collected:
 - Check the “Expired” box
 - Enter the date that baby passed away
 - Submit the filter paper form to the OSDH PHL

This is a zoomed-in view of the top section of the Oklahoma Newborn Screening (NBS) form. The 'Expired' checkbox is circled in red, and the date field next to it is also circled in red. The form includes fields for SN (XXXXXXXX), a barcode, and the title 'Oklahoma Newborn Screening (NBS)'. Below the title are checkboxes for 'First Screen', 'Repeat Screen', and 'Previous NBS Lab#'. The 'Not Screened Due To' section includes 'Expired' with a date field. The 'Tests Requested' section includes 'All Tests', 'HGB Only', 'GALT', 'Phe Monitor', and 'CFTR'. The section is titled 'BABY'S INFORMATION'.



Filling out the Form: Specimen Information

Specimen testing will be delayed if the form is incomplete!

The image shows a full Oklahoma Newborn Screening (NBS) form. A red circle highlights the 'Transferred' checkbox in the 'Specimen Information' section. A black arrow points from this circle to a zoomed-in view of the same section in the bottom right of the slide.

- If baby is transferred prior to specimen collection:
 - Check the “Transferred ” box
 - Enter the date that baby transferred and the facility that baby was transferred to
 - It is the responsibility of the receiving facility to collect the newborn screen

This is a zoomed-in view of the 'Specimen Information' section of the NBS form. A red circle highlights the 'Transferred' checkbox, which is currently unchecked. The form also shows the 'Not Screened Due To' section with options for 'Refused' and 'Expired', and the 'Tests Requested' section with options for 'All Tests', 'HGB Only', 'GALT', 'Phe Monitor', and 'CFTR'.



Filling out the Form: Specimen Information

Specimen testing will be delayed if the form is incomplete!

The image shows a full Oklahoma Newborn Screening (NBS) form. A red circle highlights the 'Tests Requested' section, which includes checkboxes for 'All Tests', 'HGB Only', 'GALT', and 'Phe Monitor'. A black arrow points from this section to a zoomed-in view of the same section in the image below.

This image is a zoomed-in view of the 'Tests Requested' section of the NBS form. It shows the following options:

- All Tests
- HGB Only
- GALT
- Phe Monitor
- CFTR

- Tests Requested: Check all that apply.
 - All Tests- always check unless test is for HGB Only or Phe Monitor. This ensures the lab screens for all disorders on the NBS panel.
 - HGB Only- Check if repeat screen is for follow-up of initial abnormal HGB result.
 - GALT- Check GALT in addition to All Tests if there is a family history of galactosemia or if baby is on lactose-free (soy) formula at time screen is collected.
 - Phe Monitor- Check only if baby has been diagnosed with PKU (typically metabolic specialists only)
 - CFTR- Check in addition to All Tests if baby has clinical concerns for CF, meconium ileus, and/or family history of CF.



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

Oklahoma Newborn Screening (NBS) Form
To order forms, call the OSH NBS Program (800) 271-9378

DO NOT WRITE HERE

BABY'S INFORMATION

Last Name: _____ First Name: _____

Birth Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Sex: Male Female Unknown

Race (Check all that apply): White Black Hispanic Asian American Indian Pacific Islander

Collection Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Medical Record # _____ Gest. Age _____ Birth Wt. (gm) _____

Multiple Birth Order A-H

- Baby's first and last name (use legal name as displayed on the birth certificate).
- If baby's first name is unknown, "BG" or "Female", "BB" or "Male" may be used.

BABY'S INFORMATION

Last Name: _____ First Name: _____

Birth Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Sex: Male Female Unknown

Race (Check all that apply): White Black Hispanic Asian American Indian Pacific Islander

Collection Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Medical Record # _____ Gest. Age _____ Birth Wt. (gm) _____

Multiple Birth Order A-H



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

The image shows the full Oklahoma Newborn Screening (NBS) form. A red circle highlights the 'BABY'S INFORMATION' section, which includes fields for Last Name, First Name, Birth Date, Time, Sex, Race, Collection Date, Time, Medical Record #, Gest. Age, Birth Wt. (gm), Multiple Birth Order, and A-H. A black arrow points from this section to a zoomed-in view of the form.

- Sex/Gender
 - Check “Male”, “Female”, or “Unknown”

This is a zoomed-in view of the 'BABY'S INFORMATION' section of the form. A red circle highlights the 'Sex' and 'Race' fields. The 'Sex' field has three options: Male, Female, and Unknown. The 'Race' field has seven options: White, Black, Hispanic, Asian, American Indian, and Pacific Islander. The 'Race' field is labeled 'Race (Check all that apply)'.



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

Oklahoma Newborn Screening (NBS) Form
To order forms, call the ODH NBS Program (405) 271-9372

XXXXXXX

DO NOT WRITE HERE

BABY'S INFORMATION

Birth Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Sex: Male Female Unknown

Race (Check all that apply): White Black Hispanic Asian American Indian Pacific Islander

- Date & Time of birth
 - Enter the time using the 24 hour clock. For example 1PM would be entered as 13:00.

BABY'S INFORMATION			
Last Name		First Name	
Birth Date	Time	Sex	Race (Check all that apply)
___/___/___	___:___ (24 Hr Clock)	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	<input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> American Indian <input type="checkbox"/> Pacific Islander
Collection Date	Time		
___/___/___	___:___ (24 Hr Clock)		
Medical Record #	Gest. Age	Birth Wt. (gm)	Multiple Birth Order <input type="checkbox"/> A-H



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

Oklahoma Newborn Screening (NBS) Form

SN XXXXXXXX

DO NOT WRITE HERE

BABY'S INFORMATION

First Name _____

Birth Date ____/____/____ Time ____:____ (24 Hr Clock)

Sex Male Female Unknown

Race (Check all that apply)

White Black Hispanic Asian American Indian Pacific Islander

Collection Date ____/____/____ Time ____:____ (24 Hr Clock)

Medical Record # _____ Gest. Age _____ Birth Wt. (gms) _____

Multiple Birth Order A-H

- Date & Time of specimen collection
 - Ideal time for well, term newborn:
 - 24 hours + 1 minute of age*
 - Enter the time using the 24 hour clock. For example 1PM would be entered as 13:00.

BABY'S INFORMATION

Last Name _____ First Name _____

Birth Date ____/____/____ Time ____:____ (24 Hr Clock)

Sex Male Female Unknown

Race (Check all that apply)

White Black Hispanic Asian American Indian Pacific Islander

Collection Date ____/____/____ Time ____:____ (24 Hr Clock)

Medical Record # _____ Gest. Age _____ Birth Wt. (gms) _____

Multiple Birth Order A-H



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

The image shows the full Oklahoma Newborn Screening (NBS) Form. A red circle highlights the 'BABY'S INFORMATION' section, which includes fields for Last Name, First Name, Birth Date, Time, Sex, Race, Collection Date, Time, Gest. Age, Birth Wt. (gm), and Multiple Birth Order. An arrow points from this section to a zoomed-in view of the same section on the right.

- Medical record number
 - Baby's medical record number

This is a zoomed-in view of the 'BABY'S INFORMATION' section of the NBS form. The 'Medical Record #' field is circled in red, indicating its importance. The section also includes fields for Last Name, First Name, Birth Date, Time, Sex, Race, Collection Date, Time, Gest. Age, Birth Wt. (gm), and Multiple Birth Order.



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

Oklahoma Newborn Screening (NBS) Form

SN: XXXXXXXX

DO NOT WRITE HERE

BABY'S INFORMATION

Last Name: _____ First Name: _____

Birth Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Sex: Male Female Unknown

Race (Check all that apply): White Black Hispanic Asian American Indian Pacific Islander

Collection Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Medical Record #: _____ Gest. Age: _____ Birth Wt. (gm): _____

Multiple Birth Order: A-H

- Gestational Age
 - List gestational age at birth.
 - Lab cut off values for abnormal severe combined immunodeficiency (SCID) are gestational age dependent.

BABY'S INFORMATION

Last Name: _____ First Name: _____

Birth Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Sex: Male Female Unknown

Race (Check all that apply): White Black Hispanic Asian American Indian Pacific Islander

Collection Date: ___/___/___ Time: ___:___ (24 Hr Clock)

Medical Record #: _____ **Gest. Age**: _____ Birth Wt. (gm): _____

Multiple Birth Order: A-H



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

The image shows a screenshot of the Oklahoma Newborn Screening (NBS) Form. A red circle highlights the 'BABY'S INFORMATION' section, which includes fields for Birth Date, Time, Sex, Race, Collection Date, Time, Medical Record #, Gest. Age, and Birth Wt. (gm). A black arrow points from this section to a zoomed-in view of the same section on the right.

- Birthweight (in grams)
 - Lab cut off values for abnormal congenital adrenal hyperplasia (CAH) results are dependent on birth weight.

BABY'S INFORMATION			
Last Name		First Name	
Birth Date	Time	Sex	Race (Check all that apply)
	(24 Hr Clock)	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	
Collection Date	Time		
	(24 Hr Clock)		
Medical Record #	Gest. Age	Birth Wt. (gm)	Multiple Birth Order <input type="checkbox"/> A-H



Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

The image shows a full Oklahoma Newborn Screening (NBS) form. A red circle highlights the 'BABY'S INFORMATION' section, which includes fields for Last Name, First Name, Birth Date, Time, Sex, Race, Collection Date, Time, Medical Record #, Gest. Age, Birth Wt. (gm), and Multiple Birth Order. A black arrow points from this section to a larger, zoomed-in view of the same section on the right.

- Birth order (if multiple birth is present)
 - Indicate “A”, “B”, “C”, etc. if baby is of multiple birth (twin, triplet, etc.).
 - Do NOT mark anything in this space if baby is a single birth.

BABY'S INFORMATION			
Last Name		First Name	
Birth Date	Time	Sex	Race (Check all that apply)
	(24 Hr Clock)	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	<input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> American Indian <input type="checkbox"/> Pacific Islander
Collection Date	Time	Multiple Birth Order <input type="checkbox"/> A-H	
	(24 Hr Clock)		
Medical Record #	Gest. Age	Birth Wt. (gm)	



Filling out the Form: Mom's Information

Specimen testing will be delayed if the form is incomplete!

- DHS Custody or Adoption

Note: If baby is adopted, be sure to check the **Adoption** box on the filter paper form and enter the agency/law firm information in this section. If DHS is involved, enter case worker information in this section and check the **DHS Custody** box.



Filling out the Form: Mom's Information

Specimen testing will be delayed if the form is incomplete!

The image shows the Oklahoma Newborn Screening (NBS) Form. A red circle highlights the 'MOTHER'S/GUARDIAN'S INFORMATION' section. A black arrow points from this section to a larger, detailed view of the same section on the right.

- Mom's first and last name
- Mom's mailing address:
 - Street, Apt # (if applicable), City, State, Zip
- Mom's telephone number:
 - Extremely important to include in case newborn screen results are abnormal and require follow-up.

This is a detailed view of the 'MOTHER'S/GUARDIAN'S INFORMATION' section of the form. Red circles highlight the following fields: Last Name, First Name, Address, Apt. #, City, State, Zip, Telephone #, and Alternate Telephone #.



Filling out the Form: Provider's Information

Specimen testing will be delayed if the form is incomplete!

Oklahoma Newborn Screening (NBS) Form
To view form, call the OSDH NBS Program at 800-271-9079

XXXXXXXXX

DO NOT WRITE HERE

PROVIDER'S INFORMATION

Physician Ordering NBS (Last, First)	Provider ID #
Primary Care/Follow-up Physician (Last, First)	Provider ID #

- Physician Ordering the NBS:
 - Include first and last name
 - Enter the NBS Provider ID #, if known
 - If Provider ID # unknown, document name and phone number

PROVIDER'S INFORMATION	
Physician Ordering NBS (Last, First)	Provider ID #
Primary Care/Follow-up Physician (Last, First)	Provider ID #



Filling out the Form: Provider's Information

Specimen testing will be delayed if the form is incomplete!

- Primary Care/Follow-up Physician:
 - Planned health care provider upon discharge from birthing facility
 - Include first and last name
 - Enter the NBS Provider ID #, if known
 - **Extremely important** that this is correct in case newborn screen results are abnormal and require follow up

PROVIDER'S INFORMATION	
Physician Ordering NBS (Last, First)	Provider ID#
Primary Care/Follow-up Physician (Last, First)	Provider ID #



Filling out the Form: Medical/Feeding History

Specimen testing will be delayed if the form is incomplete!

Oklahoma Newborn Screening (NBS) Form

MEDICAL FEEDING HISTORY (Check all that apply)

- Transfusion Date ____ / ____ / ____ Time ____:____ (24 Hr Clock)
- NICU/SCN
- TPN/SNAP
- Lipids/Carnitine/MCT
- Lactose-Free Formula (Soy)
- Meconium Ileus
- Family History of CF

MEDICAL/FEEDING HISTORY (Check all that apply)

- Transfusion Date ____ / ____ / ____ Time ____:____ (24 Hr Clock)
- NICU/SCN
- TPN/SNAP
- Lipids/Carnitine/MCT
- Lactose-Free Formula (Soy)
- Meconium Ileus
- Family History of CF

- Check all that apply for baby at the time of specimen collection
 - If transfused enter the date and time of transfusion
 - NICU/Special Care Nursery
 - TPN/SNAP
 - Lipids/Carnitine/MCT
 - Lactose-Free (Soy) Formula
 - Meconium Ileus
 - Family History of Cystic Fibrosis (CF)



Filling out the Form: Submitter ID

Specimen testing will be delayed if the form is incomplete!

The image shows the Oklahoma Newborn Screening (NBS) Form. A red circle highlights the 'SUBMITTER'S INFORMATION' section at the bottom of the form. This section includes fields for 'Submitting Facility's/Provider's ID #' and 'Submitter's Name/Address'. The form also contains sections for 'BABY'S INFORMATION', 'MOTHER'S/GUARDIAN'S INFORMATION', and 'PROVIDER'S INFORMATION'. The 'SUBMITTER'S INFORMATION' section is circled in red, and an arrow points from this circle to a larger, detailed view of the same section on the right.

- Submitting Health Provider ID #
 - This is the ID of the provider/facility who collected the specimen
 - Write or stamp in facility name and address

A detailed view of the 'SUBMITTER'S INFORMATION' section of the form. It contains two main fields: 'Submitting Facility's/Provider's ID #' and 'Submitter's Name/Address'. The fields are outlined in green, and the section title is in a green header bar.



Filling out the Form

Specimen testing will be delayed if the form is incomplete!

The diagram shows a specimen form with five dashed circles for identification. Below the circles are fields for SN, LOT, EXPIRATION DATE, COLLECTOR'S INITIALS, and UNIT. A red circle highlights the COLLECTOR'S INITIALS and UNIT fields.

Note: Do not touch the filter paper in any other area when writing initials and unit.

- **Unsatisfactory Specimen Follow-up**
 - Specimen collectors can place their initials and unit in the area below for identification purposes, in the event of an unsatisfactory specimen. This allows for easier identification of the individual who collected the specimen so that further education and/or training can be provided.



Collecting the Specimen



Time of Screening: Healthy Newborn

“24 hours plus one minute” of age

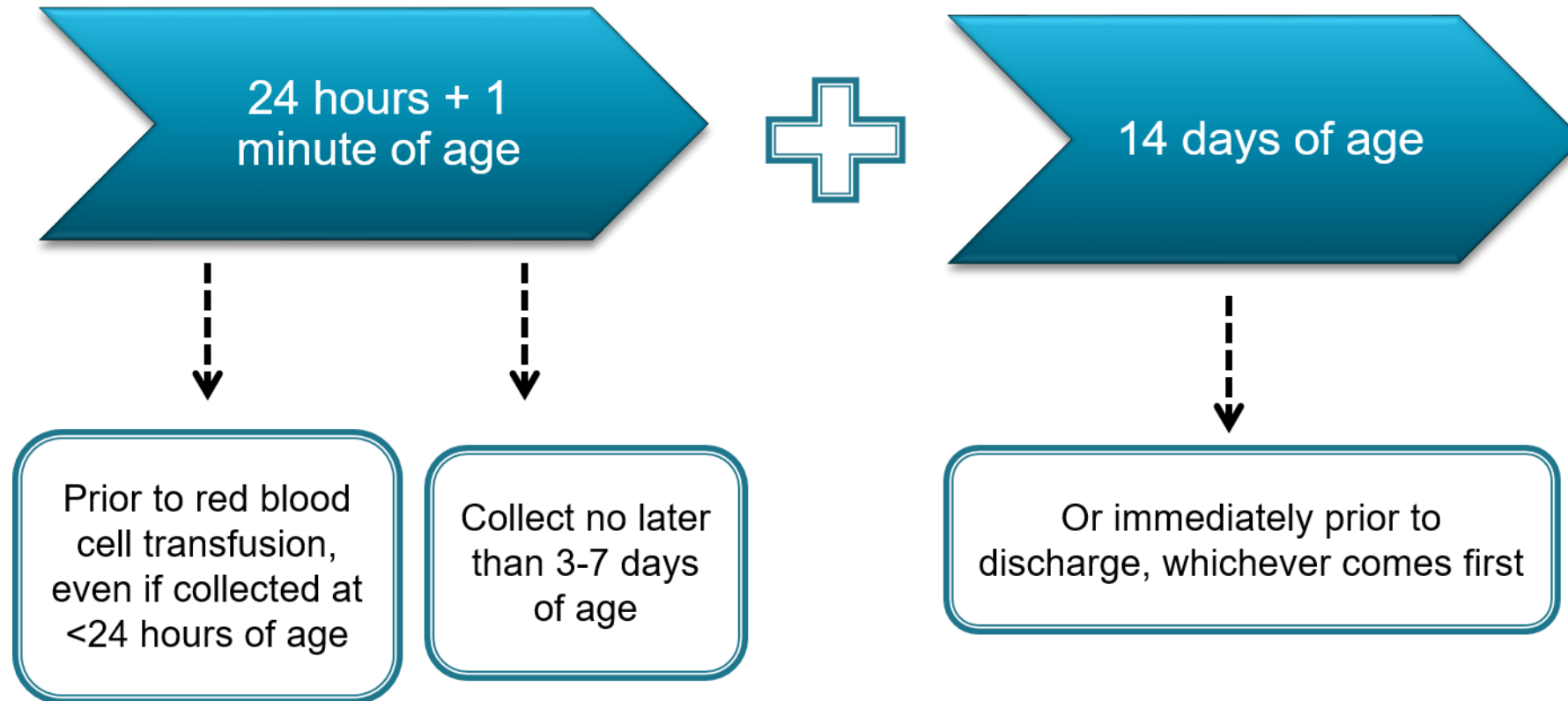
Or

Prior to discharge

****WHICHEVER COMES FIRST****

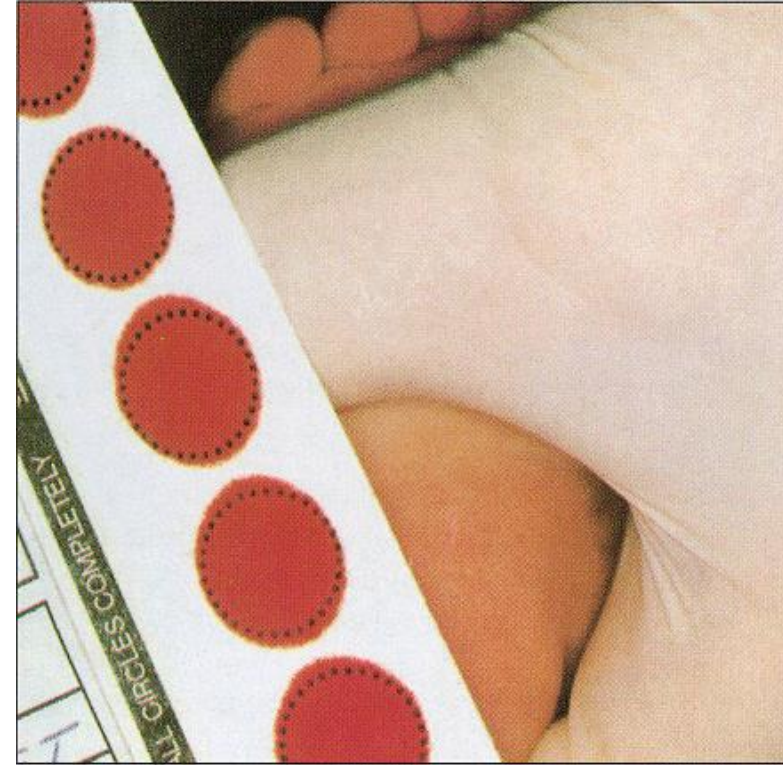


Time of Screening: Premature or Sick Newborns

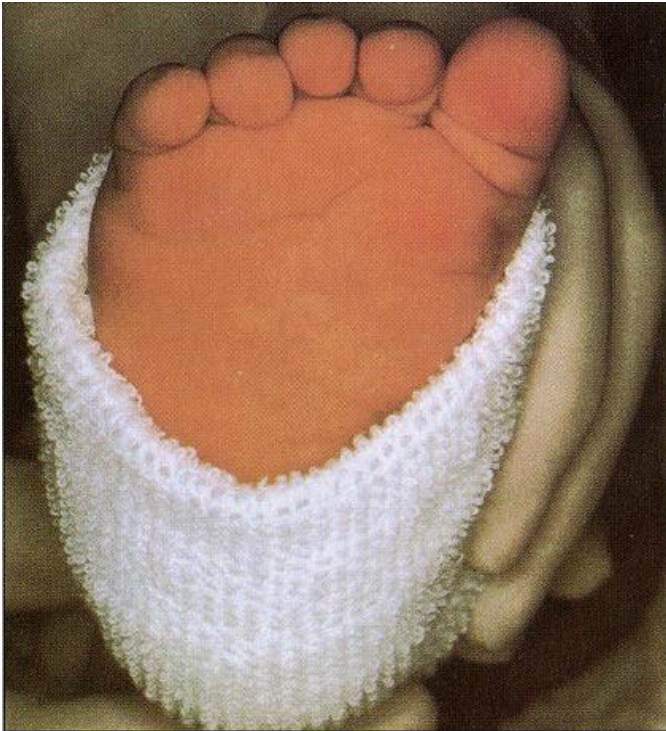


Specimen Collection

- **Heel Stick / Direct Application**
 - Preferred, recommended method
- ❖ **Start with clean, dry hands before handling the filter paper.**



Direct Application



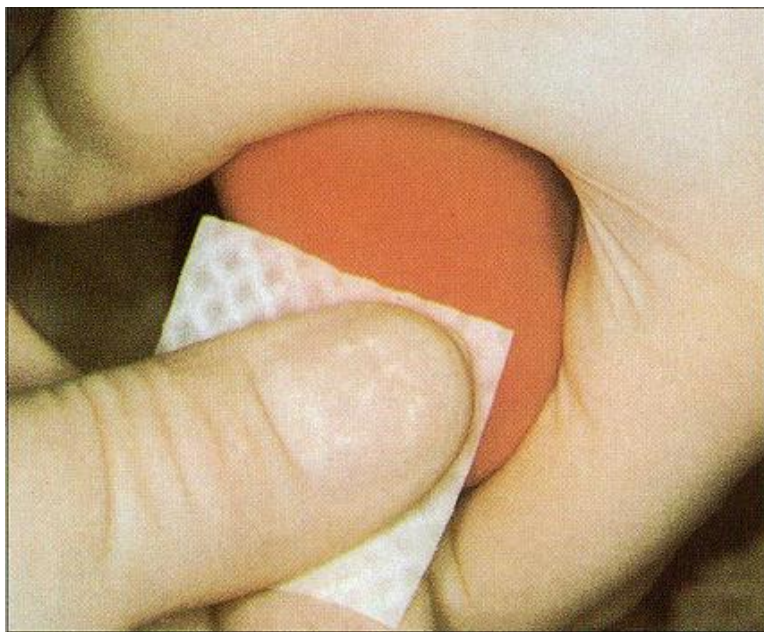
Prepare the Site

- Warm the heel with a heel warmer or a soft cloth, moistened with warm water up to 41 °C for 3 to 5 minutes.
 - Warmth leads to vasodilation, which increases bloodflow and chance of collection success.
- ❖ ***Follow your hospital protocol regarding which warming device to use***



Direct Application

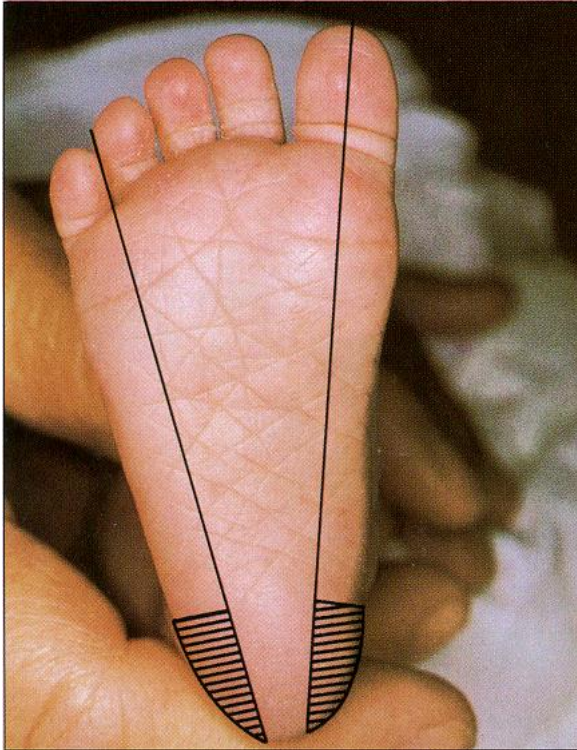
Prepare the Site



- Encourage skin-to-skin contact between newborn and parent during specimen collection.
 - Decreases stress response in newborn
 - Encourages bonding
- Position the infant's leg lower than the heart.
 - This increases venous pressure, which results in increased blood flow and a greater chance of collection success.
- Wearing gloves, wipe the infant's heel with 70% isopropyl alcohol.
- Allow the heel to air dry!
 - Residual alcohol can affect NBS results and/or lead to unsat specimens.



Direct Application



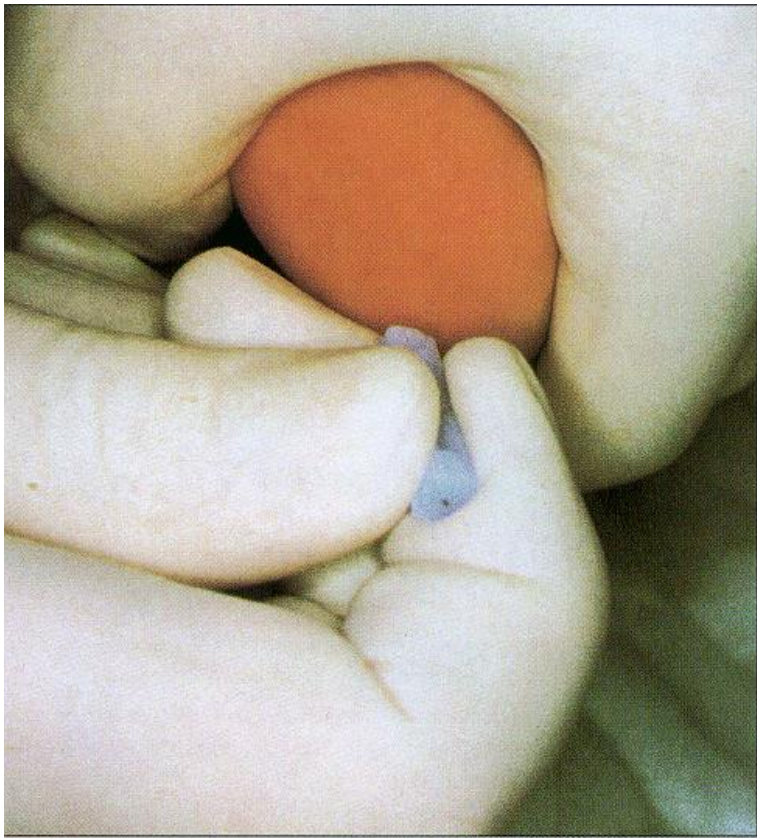
Lancet Placement

- Hatched areas are safe for puncture
- Damage to nerves and/or the heel bone may occur for punctures outside of the hatched region.



Direct Application

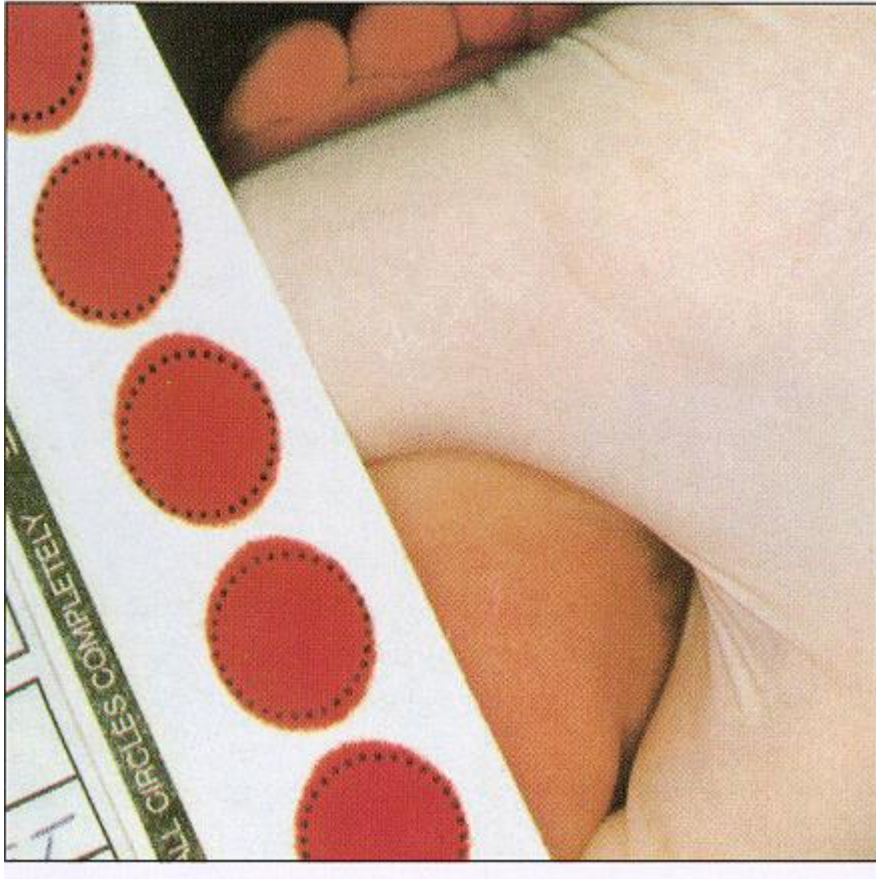
Perform the Puncture



- Using a sterile lancet, perform the puncture.
- Gently wipe off the first drop of blood with a sterile gauze or cotton ball.
- Apply gentle pressure with thumb and around heel but not near the puncture site; ease intermittently as drops of blood form.
- Avoid “milking” the puncture site.



Direct Application



Application

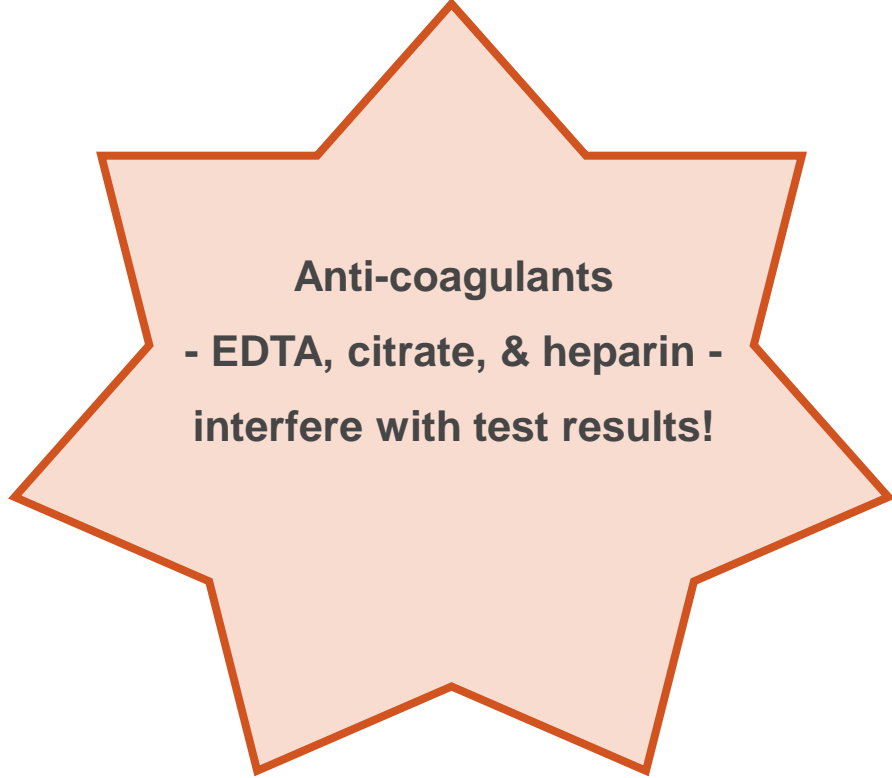
- Gently touch the filter paper card to the blood drop and fill each printed circle with **one** large drop of blood.
- Apply blood to **one** side only.
- Observe the saturation of each printed circle as the blood flows through the filter paper.



Alternative Specimen Collection

What about capillary tubes?

- **Not preferred**
 - Higher risk for collection error
- If used, must be sterile/clean & plain.
 - No additives! Must be anti-coagulant free.
 - However... no anti-coagulants = risk for clotting
- Risk of scratching the filter paper.
 - Avoid touching the capillary tip to the paper.
- Use a new tube for each pre-printed circle.



Anti-coagulants
- EDTA, citrate, & heparin -
interfere with test results!



Alternative Specimen Collection

What about venous samples?

- **Discouraged**
- May be appropriate under certain circumstances (e.g. NICU).
- More invasive than a heel stick.
- Do not draw blood from extremity with infusing IV fluids.

- Please refer to current CLSI guidelines for more information.



Alternative Specimen Collection

What about umbilical catheters?

- **Discouraged**
- May be appropriate under certain circumstances (e.g. NICU).
- Ensure the line is cleared by withdrawing 2 – 2.5 cc (mL) of blood prior to collection a specimen for NBS.

- Please refer to current CLSI guidelines for more information.



Alternative Specimen Collection

What about umbilical cord blood?

- **Discouraged**
- May be appropriate under certain circumstances (e.g. NICU).
- Risk for maternal blood contamination.
- Repeat the newborn screen using the heel stick method when indicated.

- Please refer to current CLSI guidelines for more information.



Specimen Collection: What NOT to Do

- Do NOT dab or “color in” the filter paper circles.
- Do NOT apply multiple drops of blood per circle.
- Do NOT scratch the filter paper.
- Do NOT contaminate specimens.
 - insufficient drying of alcohol, oils on hands, lotions, compressing the circles, spills, etc..
- Do NOT stack specimens.
 - risk for leaching & cross-contamination between specimens
- Do NOT submit wet specimens.
- Do NOT place specimens in direct sunlight or in front of air vents or other sources of moving air.
- Do NOT place specimens in plastic bags.
- Do NOT batch (hold onto) specimens.

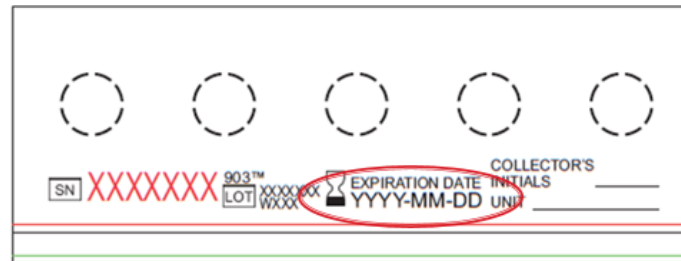


Collection Reminders

Pre-collection:

- **Check the Expiration Date of the filter paper**

If filter paper is expired, discard the paper, check the stock of filter paper kits it came from to ensure they are not all expired, and collect on a kit that is not expired.



Post-collection:

- **Air dry specimen horizontally for 3-4 hours**
 - Transporting wet specimens can make them unsatisfactory for testing.
- **Send specimen with Courier within 24 hours of collection**
 - Delayed receipt of specimens to the Public Health Laboratory can delay identification of and treatment for a disorder, which can result in lifelong disability or even death for Oklahoma newborns.
 - Know the courier schedule and location for your facility! Ensure all staff involved in newborn screening are also aware of the process.
- **Maintain specimen collection log & ensure screening results are received & recorded**
- **Ensure that everybody who handles the filter paper or is involved in the newborn bloodspot collection process is trained**



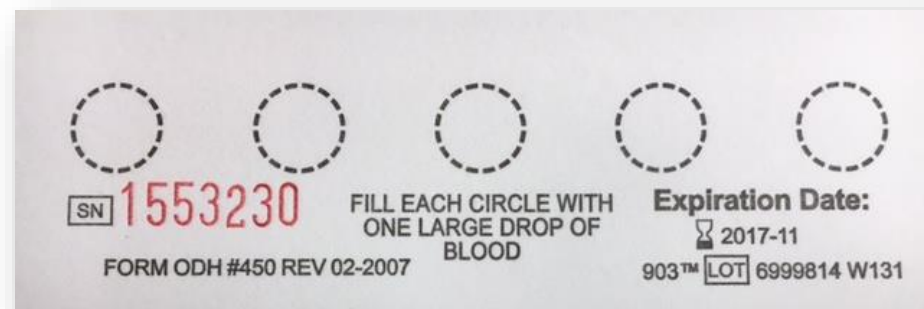
NBS Filter Paper Review

Unsatisfactory (“Unsat”) Specimen Examples



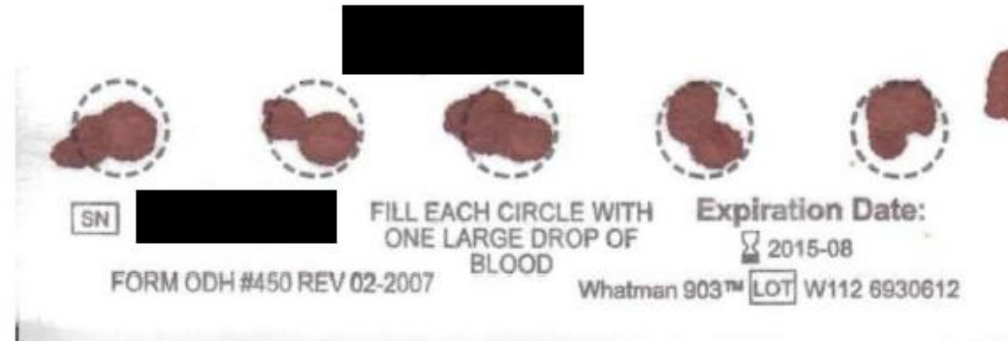
Filter Paper

- The filter paper is part of the NBS Form. It is a medical device designed to absorb a specific volume of blood within each pre-printed filter paper circle.
- If an analyte for any disorder is either too high or too low, this is an indication that additional testing is needed.
- Accurate results depend upon proper absorption of blood onto the filter paper.
 - Too much or too little blood may result in inaccurate results.



Multiple Application

Front



Back



Back

Why Unsat?

- When bloodspots overlap or touch, as is the case in the sample above, it creates an uneven absorption of blood.
- Analyte levels cannot be accurately measured.
- Testing these specimens will result in inaccurate results.



Clotted or Caked Blood



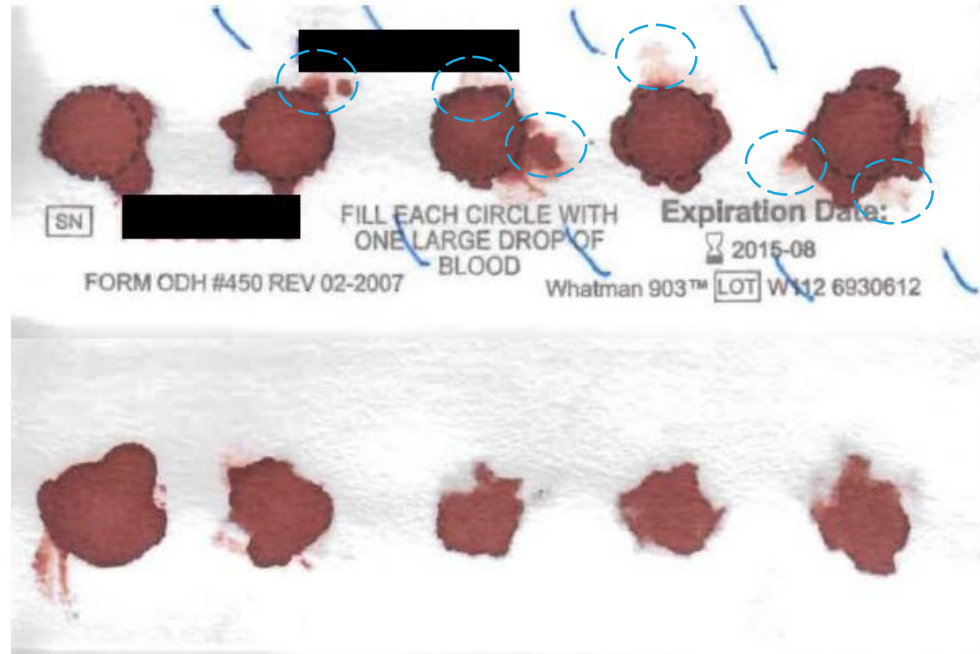
Why Unsat?

- Clots can occur using capillary tubes or if too much blood is applied to the pre-printed circles.
- Samples with clots are not suitable for testing.



Serum Rings

Front



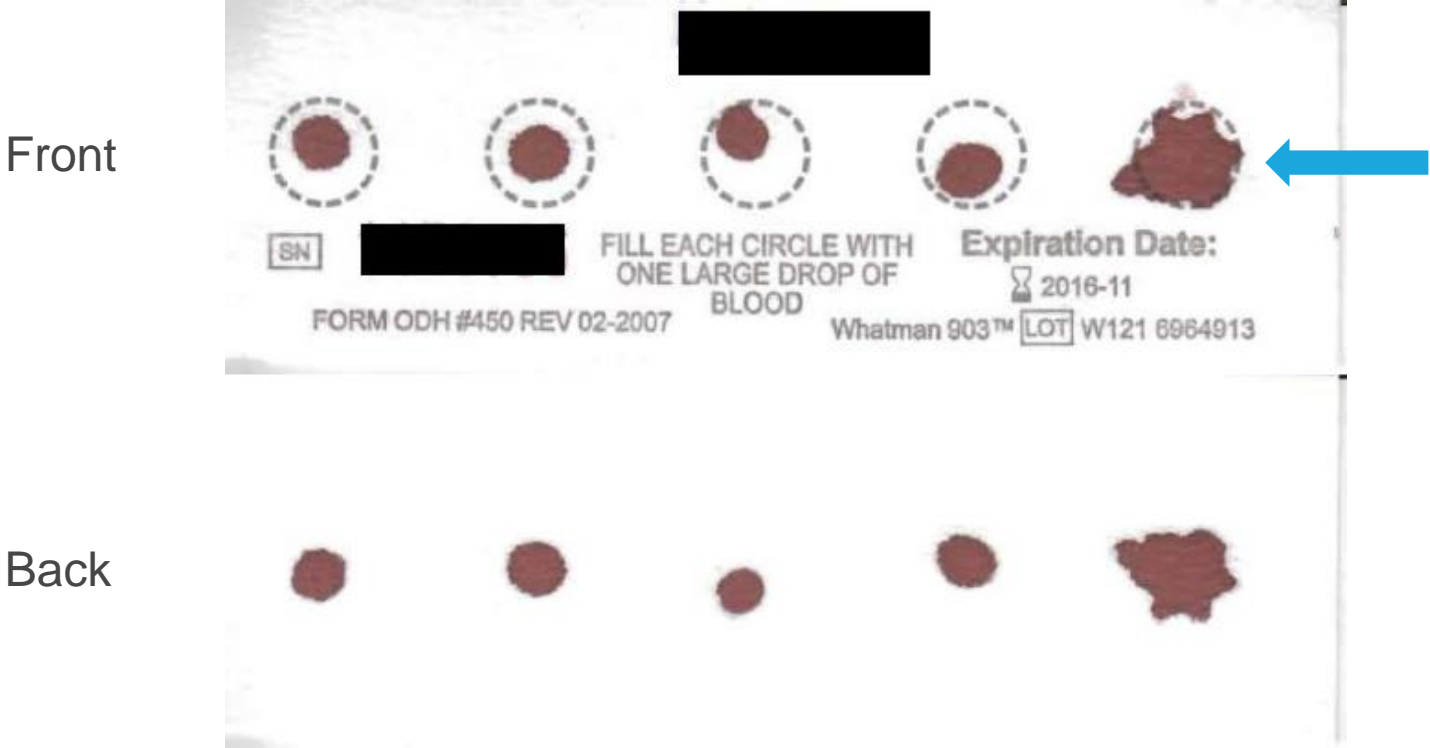
Back

Why Unsat?

- Notice the halos around the periphery of most of the pre-printed circles above. This can occur due to the following:
 - Insufficient drying of alcohol on the baby's heel prior to heelstick
 - Drying the specimen vertically instead of horizontally
 - Closing the flap of the filter paper on top of the circles while the specimen is still wet
 - Placing wet specimens in plastic bags
 - Milking or squeezing the puncture site



Inadequate Amount of Blood

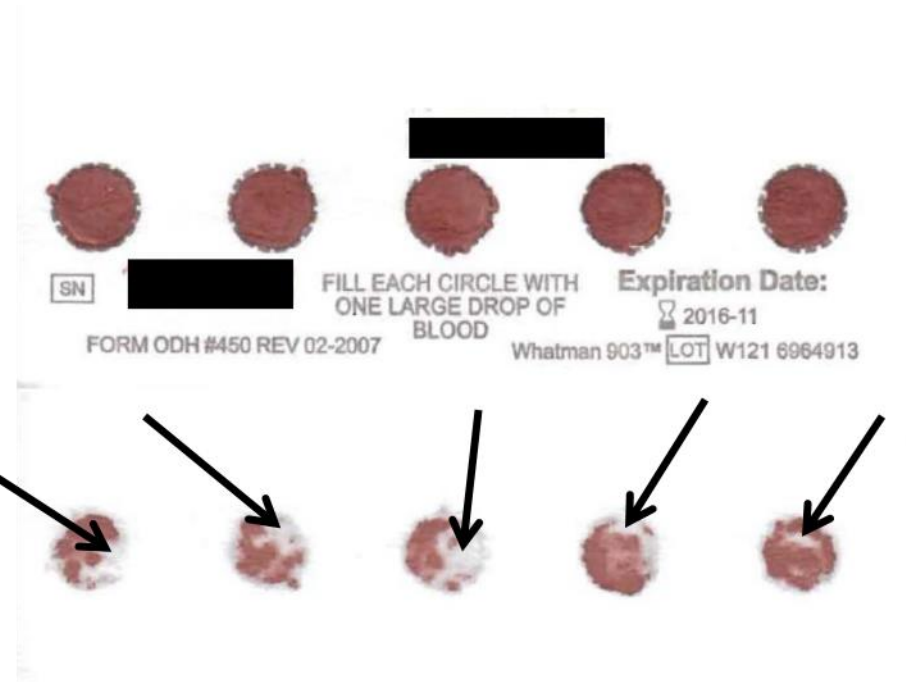


Why Unsat?

- The above filter paper circles are not sufficiently filled with blood for testing.

Under-Saturation

Front



Back



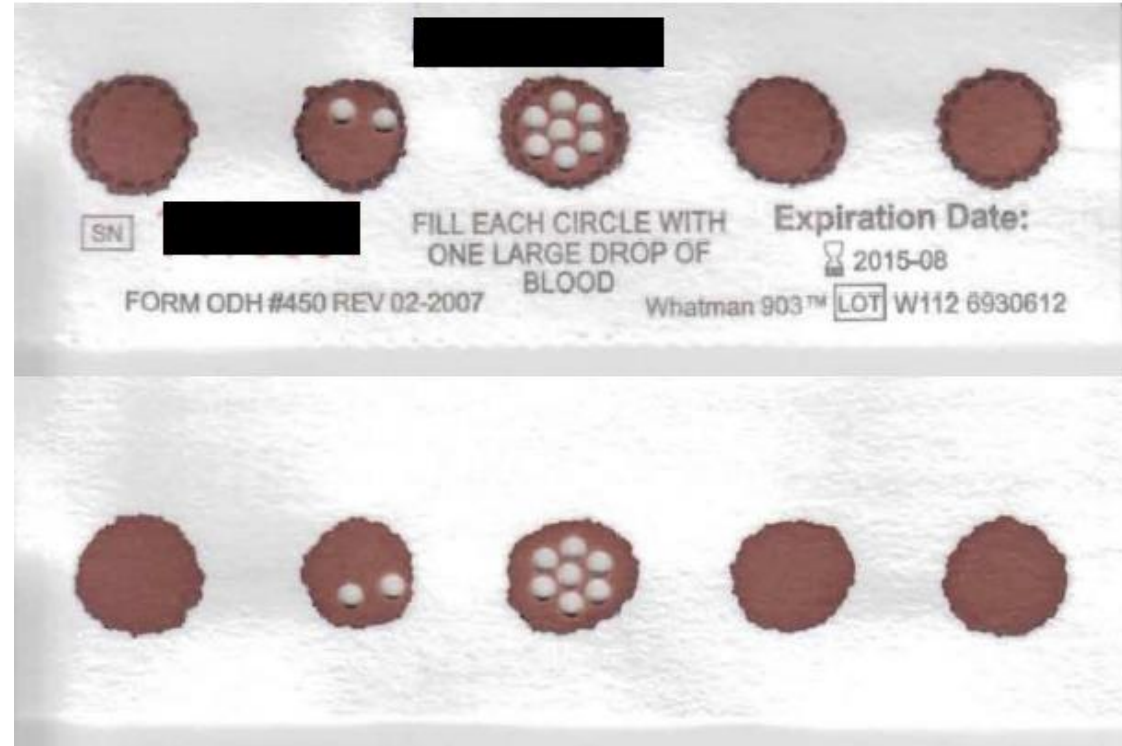
Why Unsat?

- Notice how the blood has not soaked all the way through the filter paper. There simply is not enough blood in this sample for testing.



Acceptable Filter Paper

Front



Back

Why Acceptable?

- Pre-printed circles are completely filled with blood
- Blood has soaked all the way through the filter paper
- Absence of clots or caked blood
- Absence of serum rings



Are All 5 Circles Needed?



Why?

- If a result is flagging out-of-range, the specimen will be retested and the final result will be an average of three results. Each test requires an additional punch to be taken from the pre-printed circles.
- If the results for Congenital Adrenal Hyperplasia (CAH) are out-of-range, **two entire pre-printed circles** will be removed & shipped to another laboratory for steroid profile testing.
- Disorders will continue to be added to the newborn screening panel.
- The specialist and family may request for the specimen to be sent to another laboratory for additional testing to assist in determining diagnosis.



For Reference...

- Refer to *Clinical and Laboratory Standards Institute (CLSI)* for collection guidelines.



NICU & Special Considerations



NICU Special Considerations

Infant

- Prematurity & LBW may affect TSH & 17-OHP results
- Hypoxia, CMV, septicemia, trisomies, biliary atresia may affect IRT levels
- Liver immaturity may affect amino acid results
- Carrier status may affect all NBS results

Treatment

- TPN, SNAP, & carnitine may affect amino acid, fatty acid, or organic acid results
- Steroids may affect 17-OHP results
- ECLS & blood transfusions may affect all NBS results

Maternal

- PTU therapy or radioactive iodine may affect infant TSH results
- Steroids may affect infant 17-OHP results

Collection Issues

- Contamination: oils/lotion from hands, spills, standing water, residual alcohol, heat/humidity
- Early/delayed specimen collection
- Transit time delays
- Unsatisfactory specimens



Additional Information



Hospital Responsibilities

- Ensure **all** infants are screened prior to discharge.
- Ensure specimens are received in a timely manner to the OSDH PHL for testing.
- Infants who are transferred:
 - Receiving hospital to ensure the NBS is collected.
- Submit **Satisfactory** specimens:
 - Collected properly
 - **All** requested information is documented on the filter paper
 - Submitted timely



Refusal

- Religious Tenets and Practices only.
- **Check the box(es) on the filter paper form if parents refuse the NBS and/or the pulse oximetry screen.**
 - Provide parents with a NBS blood spot and/or pulse oximetry brochure(s) & answer any questions they might have about the screen(s).

The image shows two versions of the Oklahoma Newborn Screening (NBS) form. The left form is a full filter paper form with red circles around the 'Not Screened Due To' and 'Refused' options. The right form is a zoomed-in view of the 'BABY'S INFORMATION' section, also with red circles around the 'Not Screened Due To' and 'Refused' options. Arrows point from the left form to the right form.

Left Form (Filter Paper):

- SN: XXXXXXXX
- Not Screened Due To: Refused Expired
- Refused: Religious Tenets and Practices

Right Form (Zoomed-in):

- SN: XXXXXXXX
- Not Screened Due To: Refused Expired
- Transferred: to _____
- Tests Requested: All Tests HGB Only GALT Phe Monitor CFTR
- PULSE OXIMETRY/CCHD SCREEN: Pass Fail Not Performed Refused Echo

- Ensure the parents fill out a Refusal Form. Keep a copy for baby's record & fax a copy to the NBS Program using fax # 405-900-7556.



Transit Time

Prompt delivery of specimens to the Public Health Laboratory for testing can make all the difference.



Transit Time: What is it?

- “The time between the collection of a newborn screening specimen to its receipt at the OSDH Public Health Laboratory for testing.”



Transit Time

- **Guidelines:**

- Specimens should be received at the OSDH Lab within **48 hours** from the time of collection.
- Oklahoma Law: *OS 63 Sections 1-533 and 1-534*

Delays in receiving the specimen

Delays in testing the specimen

Delays in diagnosis & treatment



Transit Time: Tips for Improvement

- Ensure everyone involved in NBS collection/handling knows about courier pick-up time, location, and importance.
- Do not batch specimens.
- Ensure the NBS is collected at 24 hr + 1 min of age & goes out with the courier as soon as possible after it has dried (~3-4 hours of drying time).
- Set timelines and goals specific for your facility.
- Maintain a courier/transport log.
- Review transit time reports.
- Contact the PHL if the courier does not present to pick up the NBS specimens.



Pulse Oximetry Screening



Pulse Oximetry Screening

Purpose:

- Screen **all** newborns between 24-48 hours of life with pulse oximetry to detect select defects related to critical congenital heart disease.

Rationale

- Some newborns may appear healthy at first *despite* having a CCHD. Early detection and prompt treatment can prevent lifelong disability and early death.

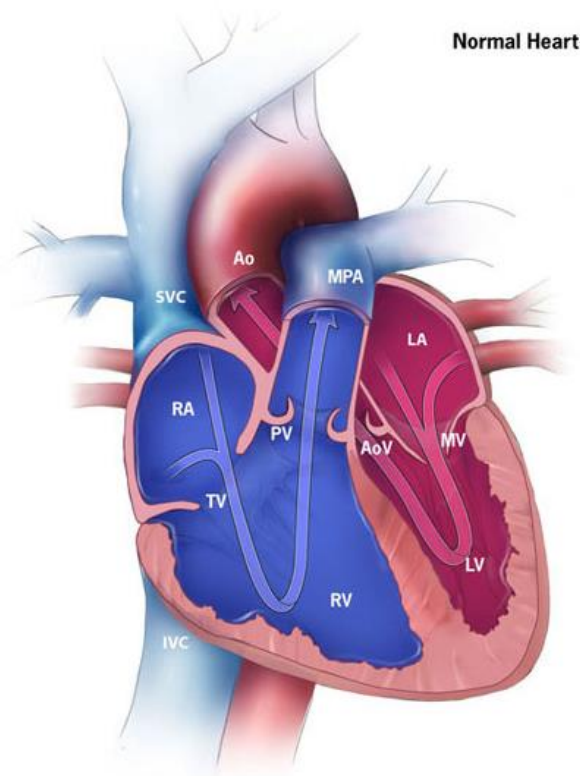


Implications

- Congenital heart disease is the **most common** birth defect
- 1 in 110 infants will have a heart defect
 - **25%** of those cases will have a CCHD
- Most affected are asymptomatic early on
- Most will require surgery shortly after birth



Normal Heart: Blood Flow



RA. Right Atrium
RV. Right Ventricle
LA. Left Atrium
LV. Left Ventricle

SVC. Superior Vena Cava
IVC. Inferior Vena Cava
MPA. Main Pulmonary Artery
Ao. Aorta

TV. Tricuspid Valve
MV. Mitral Valve
PV. Pulmonary Valve
AoV. Aortic Valve

Image credit: CDC (2014)

- Blood from body tissues goes to the right side of the heart and enters the lungs, where the blood becomes oxygenated. The blood is then delivered to the left side of the heart, which is responsible for pumping the oxygenated blood out to the body in order to provide oxygenation to the body tissues. After being utilized, the deoxygenated blood is returned to the right side of the heart, and the cycle continues. Valves within the heart help to prevent backflow of blood during this process.
- Fetal openings between the atria, ventricles, and blood vessels begin to close shortly after birth.



Fetal-Neonatal Circulation

- The first *breath of life* leads to important changes in neonatal circulation:
 - Makes way for use of neonatal lungs (The lungs were not utilized in utero, as the placenta provided oxygenation to the fetus; after birth, however, an enormous amount of pressure is necessary in order for the newborn to close the diversions used to bypass the lungs in utero and instead allow for use of the lungs.)
 - Increased pressure change in the left side of heart compared to the right (The left side becomes the body's "pump") resulting in:
 - Closure of the Ductus Arteriosus (fetal opening between aorta and pulmonary artery)
 - Closure of the Foramen Ovale (fetal opening between the right and left atria)
- ❖ *Failure of closure of fetal openings can result in complications*



CCHD: Screening Targets & Symptomatology



CCHD Targets

Most likely detected by pulse oximetry screening

- Hypoplastic Left Heart Syndrome (HLHS)
- Pulmonary Atresia
- Tetralogy of Fallot
- Total Anomalous Pulmonary Venous Return
- Transposition of the Great Arteries
- Tricuspid Atresia
- Truncus Arteriosus

❖ *These heart defects lead to low levels of oxygen in the blood.*



CCHD Targets

Potentially detected by pulse oximetry screening

- Double Outlet Right Ventricle (DORV)
- Ebstein's Anomaly
- Coarctation of the Aortic Arch
- Interruption of the Aortic Arch
- Single Ventricle

❖ *Also potentially detected by pulse oximetry screening: other hypoxic cardiac or non-cardiac conditions.*



CCHD: What to Watch For

Signs:

- Cyanosis
 - Tachypnea
 - Increased work of breathing
 - Swelling
 - Tires easily during feeds
 - Sweating
 - Poor weight gain
- ❖ **If at any time, the newborn should become symptomatic, the family should *immediately* take the baby to the closest emergency room for evaluation.**



Pulse Oximetry: the Screen & the Oximeter



Pulse Oximetry: Context

Who is screened?

- **All** newborns:
 - Must be calm & well; not crying
 - Warm extremities (temperature affects readings)
 - Skin clean & dry (dried blood affects readings)
 - Using room air; not on supplemental oxygen

When is screening performed?

- **Healthy Newborn:** Between 24-48 hours of life
- **Sick Newborn:** Between 24-48 hours of life
 - May delay if on supplemental oxygen
- **Before 24 hours:** higher risk for false positives (fetal-neonatal circulation transition not fully established)
- **After 48 hours:** delayed identification & treatment of affected newborns



The Pulse Oximeter

What is it?

- **Screening tool:** measures the percent of oxygen saturation of hemoglobin in the blood; and pulse rate
 - Simple
 - Painless
 - Non-invasive
 - Quick



The Pulse Oximeter

Oximeter Probe: 2 main parts

- light emitter
- Photodetector

Where is the probe placed?

- Right hand: preductal measurement
- Either foot: postductal measurement



Points to Consider

- Pulse oximeter must be FDA approved (AAP, 2015)
- Regular calibration of the oximeter is required
- Pulse oximetry readings are averages
- Skin color and jaundice **do not** affect pulse oximetry readings
- ❖ ***Continuous pulse oximetry monitoring does not replace the pulse oximetry screen.***



Screening How-To, Protocol, & Guidelines



How is the Screen Performed?

1. **Select site:** right hand; either foot.
2. **Place** photodetector on outer aspect of hand/foot (under 4th-5th finger/toe).
3. **Wrap** sensor tape around extremity.
4. **Ensure** light emitter is **directly opposite** the photodetector.
5. If using a reusable sensor, secure the sensor using wrap recommended by vendor; **do not tape** or use hand to secure sensor to site.



Photo credit: Masimo 2011



Guidance for Screeners

Pulse Ox Dos

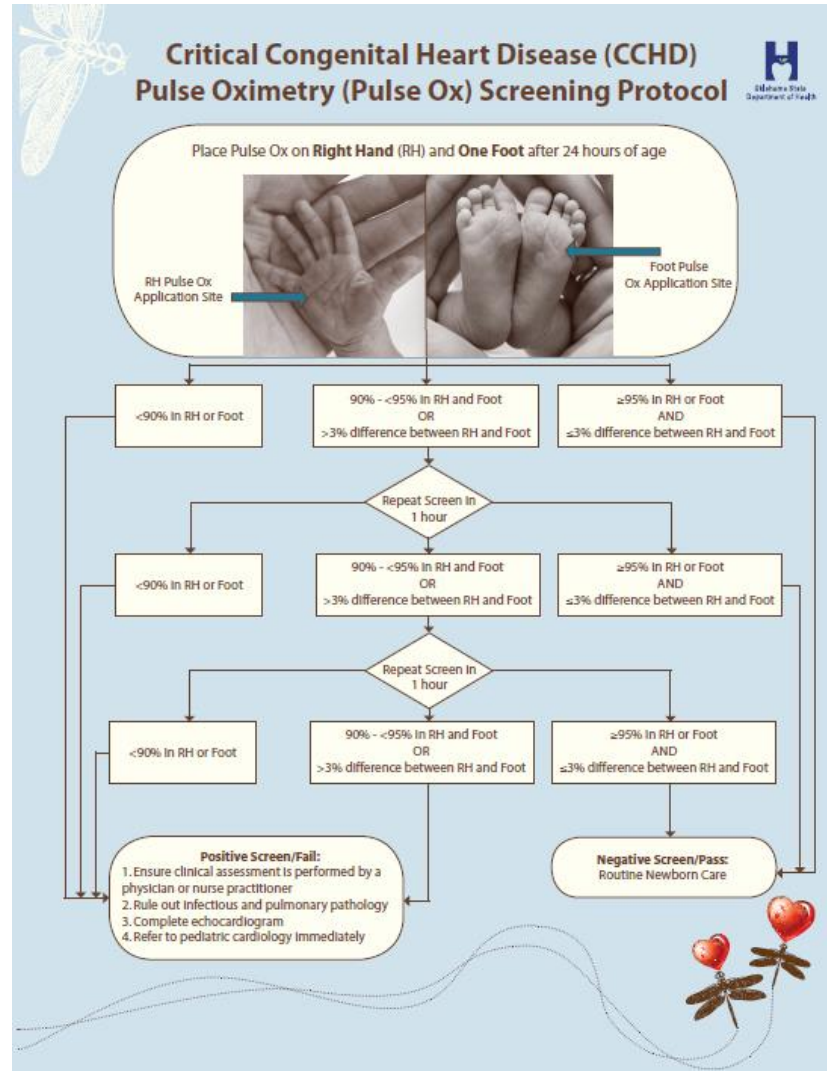
- If disposable, use a new, clean sensor; if reusable, clean between use
- Clean according to manufacturer recommendations
- Ensure newborn is calm and warm, not crying; encourage family involvement
- Ensure newborn skin is clean and dry
- Ensure no gaps between sensor and newborn's skin
- Light emitter and photodetector should be **directly opposite** of one another
- Use alongside physical examination
- Ensure pulse: no pulse, no oximetry!

Pulse Ox Don'ts

- Do not use an adult probe
- Do not tape pulse oximeter in place (use disposable wrap as indicated)
- Do not use your own hand to hold sensor in place
- Do not obtain reading from same extremity with blood pressure cuff
- Bilirubin lamps & surgical lights can affect accuracy of reading; cover pulse oximetry sensor with a blanket if such instruments are in use
- Do not use in isolation



Pulse Oximetry Screening Protocol



Interpretation of Results & Follow-Up



Screening Results

Negative Screen (Pass):

- Oxygen saturation $\geq 95\%$ in Right Hand and/or Left or Right Foot
- AND**
- Difference between the Right Hand and Left/Right Foot $\leq 3\%$

Positive Screen (Refer/Fail):

- Oxygen saturation $< 90\%$ in Right Hand or Left/Right Foot during **any** screen
- Oxygen saturation 90 - 94% for **all** 3 screens (1 hour between each screen)
- Difference between the Right Hand and Left/Right Foot $> 3\%$ for **all** 3 screens (1 hour between each screen)

❖ **If at *any* time, the newborn should become symptomatic, the family should *immediately* take the baby to the closest emergency room for evaluation.**



Interpretation of Results

Negative = Pass

- Results are in-range
- Blood oxygen level WNL
- CCHD still possible (if symptomatic, a cardiac evaluation is warranted)
- Monitor baby's status:
 - Heart rate – too fast/slow?
 - Energy – overly sleepy/fussy/lethargic?
 - Appearance – pale/blue skin?
 - Respiration – too fast/slow?
 - Temperature – cold to touch?
 - Feeding – difficulties?

Positive = Fail/Refer

- Results are out-of-range
- Blood oxygen level is low
- High risk; not diagnostic
- Confirmatory procedures & referral for treatment are warranted



Pulse Oximetry Screening for Critical Congenital Heart Defects (CCHDs) in Newborns without Cardiovascular or Respiratory Distress

Interpretation of Pulse Oximetry Results

Oxygen Saturation (%)

Right Hand (RH)	Either Foot (F)											
100	100	99	98	97	96	95	94	93	92	91	90	89 or lower
99	100	99	98	97	96	95	94	93	92	91	90	89 or lower
98	100	99	98	97	96	95	94	93	92	91	90	89 or lower
97	100	99	98	97	96	95	94	93	92	91	90	89 or lower
96	100	99	98	97	96	95	94	93	92	91	90	89 or lower
95	100	99	98	97	96	95	94	93	92	91	90	89 or lower
94	100	99	98	97	96	95	94	93	92	91	90	89 or lower
93	100	99	98	97	96	95	94	93	92	91	90	89 or lower
92	100	99	98	97	96	95	94	93	92	91	90	89 or lower
91	100	99	98	97	96	95	94	93	92	91	90	89 or lower
90	100	99	98	97	96	95	94	93	92	91	90	89 or lower
89 or lower	100	99	98	97	96	95	94	93	92	91	90	89 or lower

Pass/Negative 95 % or higher in right hand (RH) or either foot (F) AND difference of 3% or less between RH and F.

Rescreen 90-94% in RH and F OR difference of 4% or more between RH and F. Screen up to 3 times, 1 hr btwn each screen.

Fail/Positive 89% or lower in RH or F (at any time)
OR
3rd screen: 90-94% in RH and F OR difference of 4% or more between RH and F.

Reference:

Michigan Department of Community Health. Critical Congenital Heart Disease Newborn Screening Program. (2013). Pulse ox screening visual aid. Retrieved from http://www.michigan.gov/documents/mdch/PO_Screen_Graphic_422859_7.pdf

Reporting Results for CCHD: Filter Paper

The image shows a portion of the Oklahoma Newborn Screening (NBS) Form. The section titled "PULSE OXIMETRY/CCHD SCREEN" is circled in red. It contains five checkboxes: Pass, Fail, Not Performed, Refused, and Echo. A black arrow points from this section to a larger, detailed view of the same section below.


- Pulse Oximetry Screen: Check Only ONE
 - Pass
 - Fail
 - Not Performed
 - Refused
 - Echo

Note: If parents refuse the pulse oximetry screen, provide them with a pulse oximetry brochure and answer any questions they might have about the screen. Ensure the parents fill out a Refusal Form; keep a copy for baby's record & fax a copy to the NBS Program using fax # 405-900-7556.

This is a detailed view of the "PULSE OXIMETRY/CCHD SCREEN" section. It features a green header with the title in white. Below the header, there are five checkboxes with corresponding labels: Pass, Fail, Not Performed, Refused, and Echo.



Reporting Results for CCHD Pulse Oximetry Result Form

 OKLAHOMA
State Department
of Health

Oklahoma State Department of Health
Pulse Oximetry Screening Result Form

Infant Information:

Infant's Last Name: _____ Infant's First Name: _____
Medical Record Number: _____ Attending Physician/Midwife: _____
Date of Birth: ____/____/____ Birth Hospital: _____
Mother's Last Name: _____ Mother's First Name: _____

Pulse Oximetry Screening:

Date of Screening: ____/____/____
Age at Time of Screening: ____ Days or ____ Hours
Result: ____ Pass/Negative ____ Fail/Positive ____ Not Performed

Complete this section only if pulse oximetry screen was not performed:

Reason pulse oximetry screen not performed:

____ Early Discharge
____ Screening Not Indicated due to _____
____ Parent Refusal

Screener's Name: _____
Screener's Signature: _____ Date: ____/____/____

Form to be utilized if pulse oximetry screening results were not documented on newborn screening filter paper. Original to infant's record, provide a copy to parent, and forward copy by fax or mail to:
Oklahoma State Department of Health, Newborn Screening Program Coordinator, 1000 NE Tenth Street,
Oklahoma City, OK 73117-1299, (405) 426-8220 or 1-800-766-2223; Fax (405) 900-7556.

Health.Ok.gov



Newborn Screening Contacts

- **Bloodspot, Pulse Oximetry, & Hearing Screening**

Screening & Special Services
123 Robert S. Kerr
Oklahoma City, OK 73102-6406

Phone: 1-405-426-8220
Toll Free: 1-800-766-2223
Fax: 1-405-900-7556
NewbornScreen@health.ok.gov

- **Public Health Laboratory**

Newborn Screening Section
Public Health Laboratory Service
4615 W. Lakeview RD
Stillwater, OK 74075

Phone: 1-405-564-7750
Toll Free: 1-800-766-2223
Fax: 1-405-900-7611
Publichealthlab@health.ok.gov

