

# Newborn Screening

Oklahoma State Department of Health

Newborn Screening Program

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# Why Newborn Screening

Allow me to Introduce....

# Five Stories and Counting

Five Stories  
Five Children  
Five Diagnoses  
Two Messages

“Newborn Screening Made a Lifechanging Difference”

“Please Do Not Skip this Screen!”



**NEWBORN  
SCREENING**

Five Families, Five Stories:  
How Newborn Screening  
Changed Our Lives

**JASE'S STORY**  
Galactosemia

**CHIZM'S STORY**  
Congenital Hypothyroidism

**LAINY'S STORY**  
MCADD

**DAVID JOEL'S STORY**  
Hearing Loss

**HENRY'S STORY**  
Sickle Cell Disease

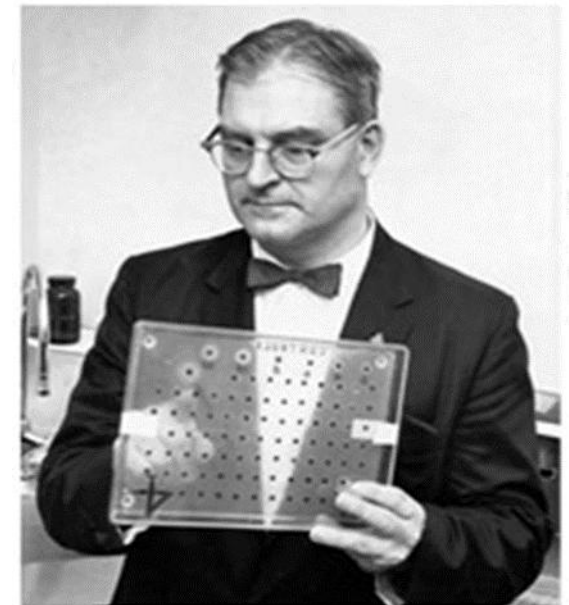
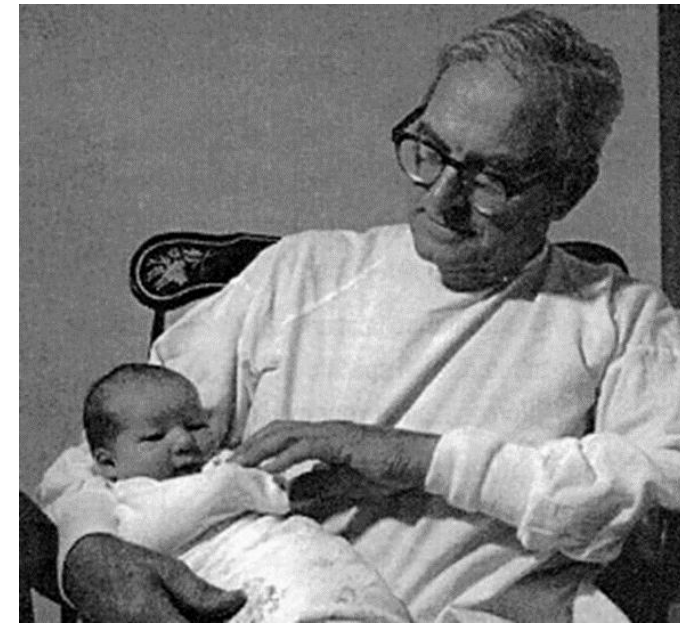
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**OKLAHOMA  
State Department  
of Health**

Screening and  
Special Services

# History of Newborn Screening

- Newborn screening **originated** with Dr. Robert Guthrie who developed a test for elevated phenylalanine in dried blood spots in **1960**. (PKU Disease)
- **Before** the blood test existed, most children with PKU were not diagnosed until after they had irreversible brain damage.
- **Early** test > **Early** diagnosis > **Early** treatment > Mitigated brain damage.
- PKU was the first condition identified by NBS, so some people still refer to all NBS as the “PKU test.” However, **this term is not accurate as the newborn screen now tests for 57 total disorders, not solely PKU.**





In Oklahoma, we screen for **OVER 50 DISORDERS.**

Using the term “PKU” can be confusing or misleading, potentially leading to errors in communication.

CONGENITAL HYPOTHYROIDISM (CH), CLASSIC GALACTAEMIA (GAL), GALACTOSEMIDASE DEFICIENCY (GAL), GALACTOKINASE DEFICIENCY (GALK), SICKLE CELL ANEMIA (HB SS), SC DISEASE (HB SC), S-BETA-THALASSAEMIA (HB S/BTH), VARIOUS OTHER HEMOGLOBINOPATHIES, CYSTIC FIBROSIS (CF), CONGENITAL ADRENAL HYPERPLASIA (CAH), BIOTINIDASE DEFICIENCY (BIO), SEVERE COMBINED IMMUNODEFICIENCY (SCID), SPINAL MUSCULAR ATROPHY (SMA), X-LINKED ADENOSINEKUDYDROPHY (X-ALD), MUCOPOLYSACCHARIDOSIS TYPE I (MPS), POMPE (POM), ADONINEMIA (AD), ADONISUCCINIC ACIDURIA (ASA), CITRULLINEMIA TYPE I (CIT), CITRULLINEMIA TYPE II (CIT II), HOMOCYSTINURIA (HCV), HYPERMETHIONINEMIA (MET), MAPLE SYRUP URINE DISEASE (MSUD), **PHENYLKETONURIA (PKU)**, BENIGN HYPERTHYROIDISM (H-PHE), BIOPTERIN DEFECT IN COFACTOR BIOSYNTHESIS (BIOP1), BIOPTERIN DEFECT IN COFACTOR DEGRADATION (BIOP2), TYROSINEMIA TYPE I (TYR I), TYROSINEMIA TYPE II (TYR II), TYROSINEMIA TYPE III (TYR III), CARNITINE UPTAKE DEFECT (CUD), SHORT-CHAIN ACYL-CoA DEHYDROGENASE DEFICIENCY (SCAD), GLUTARIC ACIDEMIA TYPE II (GAD), MEDIUM-CHAIN KETOACYL-CoA THIOLEASE DEFICIENCY (MCAT), MEDIUM-CHAIN ACYL-CoA DEHYDROGENASE DEFICIENCY (MCAD), VERY LONG-CHAIN ACYL-CoA DEHYDROGENASE DEFICIENCY (VLCAD), CARNITINE ACYL-CARNITINE TRANSLOCASE DEFICIENCY (CACT), CARNITINE PALMITOYLTRANSFERASE I DEFICIENCY (CPT I), CARNITINE PALMITOYLTRANSFERASE II DEFICIENCY (CPT II), LONG-CHAIN L-3-HYDROXYACYL-CoA DEHYDROGENASE DEFICIENCY (LCHAD), TRIMETHYLAMINE N-DETECTOR DEFECT (TND), PROPIONIC ACIDURIA (PPCA), ETHYLMALEIC ACIDEMIA (EM), METHYLMALONIC ACIDEMIA (CERAMIDE OXIDIZER) (CER AL), METHYLMALONIC ACIDEMIA WITH HOMOCYSTINURIA (CER C), MALARIC ACIDEMIA (MAL), ISOBUTYRYLGALACTURIA (IBG), BUTYRYL-CoA DEHYDROGENASE DEFICIENCY (BHD), LACTIC ACIDEMIA (LAL), METHYLCROTONIC ACIDURIA (MCA), METHYLMALONIC ACIDURIA (MMA)



OKLAHOMA  
State Department  
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NEWBORN  
SCREENING 

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# Conditions on the Oklahoma Bloodspot Testing Panel

## Congenital Hypothyroidism (CH)

### Classic Galactosemia (GAL)

Galactosepimerase deficiency (GALE)

Galactokinase deficiency (GALK)

## Sickle Cell Anemia (Hb SS)

## S,C Disease (Hb SC)

## S, $\beta$ -Thalassemia (Hb S/ $\beta$ Th)

Various other hemoglobinopathies

## Cystic Fibrosis (CF)

### Congenital Adrenal Hyperplasia (CAH)

## Biotinidase Deficiency (BIO)

## Severe Combined Immunodeficiency (SCID)

## Spinal Muscular Atrophy (SMA)

## X-Linked Adrenoleukodystrophy (X-ALD)

## Mucopolysaccharidosis Type 1 (MPS1)

## Pompe (POM)



## Amino Acid Disorders

- Argininemia (ARG)
- **Argininosuccinic aciduria (ASA)**
- **Citrullinemia type I (CIT)**
- Citrullinemia type II (CIT II)
- **Homocystinuria (HCY)**
- Hypermethioninemia (MET)
- **Maple Syrup Urine Disease (MSUD)**
- **Phenylketonuria (PKU)**
- Benign hyperphenylalaninemia (H-PHE)
- Biopterin defect in cofactor biosynthesis (BIOPT [BS])
- Biopterin defect in cofactor regeneration (BIOPT [REG])
- **Tyrosinemia Type I (TYR I)**
- Tyrosinemia Type II (TYR II)
- Tyrosinemia Type III (TYR III)

Red text indicates a time critical disorder.

# Conditions on the Oklahoma Bloodspot Testing Panel

## Fatty Acid Disorders

- Carnitine uptake defect (CUD)
- Short-chain acyl-CoA dehydrogenase deficiency (SCAD)
- Glutaric acidemia Type II (GAII)
- Medium-chain ketoacyl-CoA thiolase deficiency (MCAT)
- **Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)**
- **Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)**
- Carnitine acylcarnitine translocase deficiency (CACT)
- Carnitine palmitoyltransferase I deficiency (CPT IA)
- Carnitine palmitoyltransferase II deficiency (CPT II)
- **Long-chain L-3-hydroxyacyl- CoA dehydrogenase deficiency (LCHAD)**
- **Trifunctional protein deficiency (TFP)**

## Organic Acid Disorders

- **Propionic Acidemia (PROP)**
- **Methylmalonic acidemia (MUT)**
- **Methylmalonic acidemia (Cobalamin Disorders) (Cbl A,B)**
- Methylmalonic acidemia with homocystinuria (Cbl C,D)
- Malonic acidemia (MAL)
- Isobutyrylglycinuria (Isobutyryl-CoA dehydrogenase deficiency) (IBG)
- **Isovaleric Acidemia (IVA)**
- 2-Methylbutyrylglycinuria (2MBG)
- **3-Methylcrotonyl-CoA carboxylase deficiency (3-MCC)**
- 3-Methylglutaconic aciduria (3MGA)
- **3-Hydroxy-3-methylglutaric aciduria (HMG)**
- **Holocarboxylase synthetase deficiency (multiple carboxylase deficiency) (MCD)**
- 2-Methyl-3-hydroxybutyric aciduria (2M3HBA)
- **Beta ketothiolase deficiency ( $\beta$ KT)**
- **Glutaric acidemia type I (GA1)**



# NBS Conditions and Their Consequences When Not Diagnosed Early

| NBS Conditions, Grouped by Specialty | Potential Outcomes Without Prompt Diagnosis                                                                                      |
|--------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|
| Endocrine Disorders (CH, CAH)        | Delayed growth, brain damage, loss of life.                                                                                      |
| Immunologic (SCID)                   | Uncontrolled infections, isolation needed, loss of life.                                                                         |
| Neurologic (SMA)                     | Loss of muscle tone, to varying degree, or loss of life.                                                                         |
| Pulmonary (CF)                       | Poor growth, recurrent lung infections, FTT, shortened life span.                                                                |
| Hematology (SC and others)           | Infection, pain, poor growth, multi organ problems.                                                                              |
| Genetics (too many to list)          | Poor growth, hypoglycemia, unresponsiveness, seizures, multi organ system problems, many leading to loss of life if not treated. |



# NBS Conditions and Their Available Treatments

| NBS Conditions, Grouped by Specialty | Available Treatments                                                                                                                                             |
|--------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Endocrine Disorders (CH, CAH)        | Daily oral medication, frequent monitoring.                                                                                                                      |
| Immunologic (SCID)                   | Bone Marrow Transplant                                                                                                                                           |
| Neurologic (SMA)                     | Gene Therapy, Physical and Occupational Therapy                                                                                                                  |
| Pulmonary (CF)                       | Breathing treatments, oral medications, chest PT, frequent monitoring. Lung transplants in severe cases.                                                         |
| Hematology (SC)                      | Daily oral medication, monitoring, blood transfusions, pain control.                                                                                             |
| Genetics (too many to list)          | Dietary restrictions, dietary supplements, nutritional formulas, monitoring, enzyme replacement therapy. In more severe disorders, dialysis and hospitalization. |

All treatments are life giving or life enhancing treatments that cannot be started until the problem is identified. Without early and consistent newborn screening, sometimes we are too late to treat.



# Newborn Screening Today: A Three-Part Process

- Newborn screening checks a baby for certain conditions present at birth that benefit from early treatment or intervention.
- Blood spot screening, which determines if a baby might have one of many serious conditions.
- Pulse oximetry screening, which determines if a newborn might have certain heart conditions.
- Hearing screening, which determines if a newborn might be deaf or hard of hearing.



# Screening VS Diagnostic

- **Screening results**, by themselves, cannot determine the presence or absence of a disorder. The purpose of a screen is to detect risk factors for disease in large numbers of apparently healthy individuals – in this case, newborns.
- **Diagnostic results** refers to the combination of signs, symptoms, and test results that allows the provider to confirm the diagnosis of the respective disease.



# Autosomal Recessive

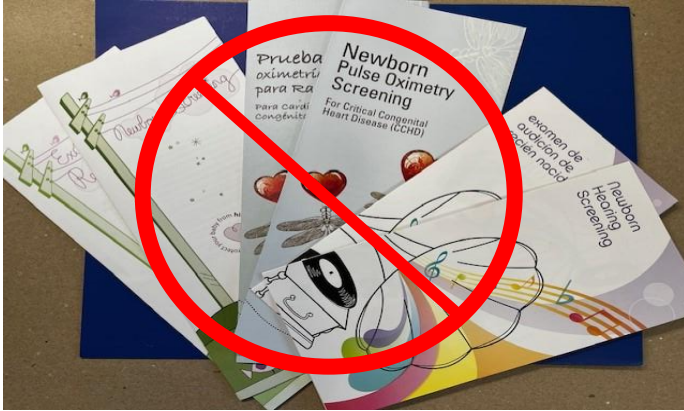
- Most NBS disorders are autosomal recessive with the exception of:
  - Congenital Hypothyroidism (CH)
  - Some forms of Severe Combined Immunodeficiency (SCID)
  - X-Linked Adrenoleukodystrophy
- Usually no prior family history
- Risk for each pregnancy if both parents are carriers of a disorder:

## Possible Outcomes for Offspring of Parental Disease Carriers



# Parent Education

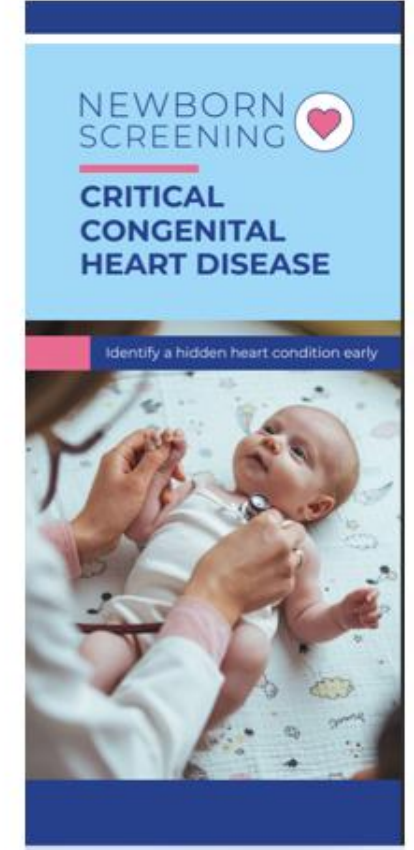
# Educational Brochure Refresh – Check your Supply



Our NBS brochures have had a “glow-up” complete with coordinated messaging and QR codes. Please check your supply and order the updated version asap with the following link:

[https://osdhcfhs.az1.qualtrics.com/jfe/form/SV\\_6r2x5bJj9GvTyg6](https://osdhcfhs.az1.qualtrics.com/jfe/form/SV_6r2x5bJj9GvTyg6)

Please dispose of old version when you receive your new supply.



# Oklahoma State Rules and Statutes – Filter Paper Education Pages

## Blood spot

**OKLAHOMA NEWBORN SCREENING PROGRAM**  
Oklahoma State Department of Health

Parent/Guardian Information Sheet

**1710050**

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 health-care 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

**OKLAHOMA NEWBORN SCREENING PROGRAM**  
Oklahoma State Department of Health

Parent/Guardian Information Sheet

**Will my baby need more testing?**  
Your baby's healthcare provider or an OSDH Newborn Screening Program coordinator will contact you if your baby needs further testing. They will tell you why more tests are needed and what to do next. Retesting does not necessarily mean that your baby is sick, but rather is done to be sure there is not a problem.

Additional testing may be needed if:

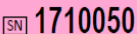
- Test results were abnormal or unclear.
- Your baby was premature or sick at birth.
- The blood sample was collected before your baby was 24 hours of age.
- Your baby had a blood transfusion before the blood sample was collected.
- There was a problem with the blood sample.
- Your baby's healthcare provider requests repeat testing.

**What if I have questions?**  
If you have questions about your baby's newborn screening tests or test results, contact your baby's healthcare provider, visit the OSDH Newborn Screening Program website at <http://nsp.health.ok.gov>, call the OSDH Newborn Screening Program at (405) 271-6617 or 1-800-766-2223 or email the program at [newbornscreen@health.ok.gov](mailto:newbornscreen@health.ok.gov)



# Oklahoma State Rules and Statutes – Filter Paper Education Pages

## Hearing Screen




**OKLAHOMA NEWBORN HEARING SCREENING PROGRAM**  
 Oklahoma State Department of Health



### Parent/Guardian Information Sheet

Baby's Last Name \_\_\_\_\_

Baby's First Name \_\_\_\_\_

**IMPORTANT**

Please, take this form with you to your baby's first well child visit to discuss the results with your baby's healthcare provider.

#### Importance of newborn hearing screening

Every baby born in an Oklahoma hospital is required to have their hearing checked before leaving the hospital. For infants born outside of a hospital, a screening should be completed no later than 1 month of life. Hearing screening is a quick, harmless and effective way to determine if an infant can hear sounds needed for proper development of speech and language. Hearing problems need to be identified as early as possible. If an infant has a hearing loss, steps can be taken to help the infant learn to communicate.

#### Will my baby need more testing?

The hearing screen results for your baby should be indicated in the box to the right.

- **"Pass"** for both ears = your infants hearing is sufficient for language development.
- **"Refer"** for one or both ears = additional testing is needed. Your baby's healthcare provider should refer you for additional hearing testing.

Hearing loss can occur at any time after birth. If your baby has any box marked under **Hearing Risk Status**, it is recommended that your baby's hearing be checked again by 6 months of age.

*If for some reason your baby's hearing was not screened, please call the Oklahoma State Department of Health Newborn Hearing Screening Program at the number indicated on the reverse of this form to ask about a location close to you where your baby's hearing can be checked.*

**HEARING SCREEN**

Date of Final Screen: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Right Ear: ☐ Pass ☐ Refer    Left Ear: ☐ Pass ☐ Refer

Screen Method: ☐ ABR ☐ OAE

If not screened, reason:

☐ Delayed  
☐ Discharged  
☐ No Supplies  
☐ Refused  
☐ Technical Problem

**Hearing Risk Status**  
(Select all that apply)

☐ Family History  
☐ In Utero Infection  
☐ Craniofacial Anomalies  
☐ ECMO  
☐ Both Hyperbilirubinemia AND Exchange Transfusion  
☐ NICU

DETACH AND GIVE TO PARENT OR GUARDIAN

**OKLAHOMA NEWBORN HEARING SCREENING PROGRAM**  
 Oklahoma State Department of Health  
**Parent/Guardian Information Sheet**

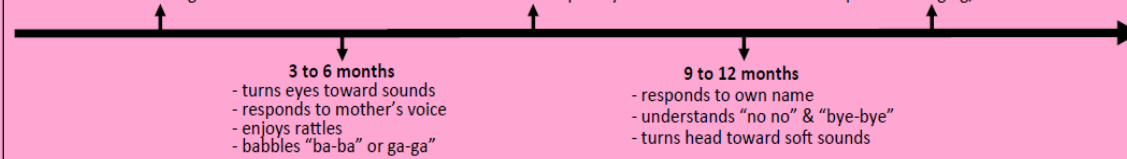
#### Your baby's hearing

Your child's most important learning and speech development will take place during the first few years of life. In these early years of development, your child learns how to communicate — first to understand what people say, and then to start talking. Any degree of undetected hearing loss can negatively impact a child's speech, language, social and emotional development.

Your baby should be able to achieve the following milestones around the ages listed below. As the weeks and months go by, check to see if your baby can do most of the things listed. *If your baby can't, don't wait— have your infants' hearing tested.* If you suspect a hearing loss or have a concern about your child's hearing, contact your healthcare provider, an audiologist, or your county health department to find out about hearing testing.

#### Hearing checklist

| Birth to 3 months                                                           | 6 to 10 months                                                                                | 12 to 15 months                                                                                                |
|-----------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|
| - startled by loud sound<br>- quiets to your voice<br>- makes cooing sounds | - turns head towards sounds<br>- begins to imitate speech sounds<br>- babbles more frequently | - correctly uses "ma-ma" and "da-da"<br>- points to familiar objects when asked<br>- responds to singing/music |



**3 to 6 months**

- turns eyes toward sounds
- responds to mother's voice
- enjoys rattles
- babbles "ba-ba" or ga-ga"

**9 to 12 months**

- responds to own name
- understands "no no" & "bye-bye"
- turns head toward soft sounds

#### What if I have questions?

If you have questions about your baby's newborn hearing test results, contact your baby's healthcare provider, visit the OSDH Newborn Screening Program website at <http://nsp.health.ok.gov>, call at (405) 271-6617 or 1-800-766-2223, or email the program at [newbornscreen@health.ok.gov](mailto:newbornscreen@health.ok.gov).



# Parent Education

- NBS is collected on **every** baby born in Oklahoma.
- Importance of **correct** contact info and PCP for follow-up.
- *No news is not good news!*
- 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 and treatment of disorders is critical.
- If a parent desires additional education, refer them to OK NBS Website.  
[www.Oklahoma.gov/health/nbs](http://www.Oklahoma.gov/health/nbs)



# Parent Refusal of Newborn Screening

Religious Tenets and Practices Only

# Refusals: What to do

1. EDUCATE USING BROCHURES: If parent is reluctant, have parent watch one of our NBS Family Story videos. Keep copies of family story pdf at the nurse's station, or a laminated one on hearing cart or other readily available location.
2. REFUSAL FORM: If parent persists in intent to refuse NBS, please complete the [NBS Refusal Form](#). This is also available for download on the OK NBS Website. Be sure and mark what is refused: **bloodspot, hearing, and/or CCHD**. Must be signed and dated by parent and witness.
3. DEMOGRAPHIC FORM: Complete entirely, marking "Not Screened Due to Refused".
4. SUBMIT: Send the Demographic Form and the Refusal Form TOGETHER to the public health lab – just as if it contained bloodspots. This is preferable to faxing or mailing the refusal form.

|                                                                                                                     |                                        |                         |
|---------------------------------------------------------------------------------------------------------------------|----------------------------------------|-------------------------|
| <input type="checkbox"/> First Screen                                                                               | <input type="checkbox"/> Repeat Screen | Previous NBS Lab# _____ |
| Not Screened Due To <input checked="" type="checkbox"/> Refused <input type="checkbox"/> Expired ____ / ____ / ____ |                                        |                         |
| <input type="checkbox"/> Transferred ____ / ____ / ____ to _____                                                    |                                        |                         |

| PULSE OXIMETRY/CCHD SCREEN    |                               |                                        |                                             |                               |
|-------------------------------|-------------------------------|----------------------------------------|---------------------------------------------|-------------------------------|
| <input type="checkbox"/> Pass | <input type="checkbox"/> Fail | <input type="checkbox"/> Not Performed | <input checked="" 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<br><input type="checkbox"/> ABR <input type="checkbox"/> OAE                                                                                                                                                              | Hearing Risk Status<br>(Select all that apply)                                                                                                                                                                                                                                           |
| If not screened, reason<br><input type="checkbox"/> Delayed<br><input type="checkbox"/> Discharged<br><input type="checkbox"/> No Supplies<br><input checked="" type="checkbox"/> Refused<br><input type="checkbox"/> Technical Problem | <input type="checkbox"/> Family History<br><input type="checkbox"/> In Utero Infection<br><input type="checkbox"/> Craniofacial Anomalies<br><input type="checkbox"/> ECMO<br><input type="checkbox"/> Both Hyperbilirubinemia AND Exchange Transfusion<br><input type="checkbox"/> NICU |



# Refusal Form

- Must be signed by parent and witness.
- If parent refuses to sign, may have two nurses sign and make notation that parent refused to sign.
- There is NO reporting to DHS or any other government agency.
- The goal remains EVERY BABY SCREENED.



**OKLAHOMA**  
State Department  
of Health

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**Newborn Screening Program  
Religious Tenets and Practices Refusal Form**

Infant's Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Gender: M / F  
 Parent/Guardian's Name: \_\_\_\_\_ Medical Record #: \_\_\_\_\_  
 Street Address: \_\_\_\_\_ Apt/Unit #: \_\_\_\_\_  
 City/State/Zip: \_\_\_\_\_ Phone #: \_\_\_\_\_  
 Place of Birth (check one): ☐ Hospital ☐ Birthing Facility ☐ Home Birth  
 Hospital/Facility Name: \_\_\_\_\_ Attending Physician/Midwife: \_\_\_\_\_  
 Child's Dr/Planned Primary Care Provider: \_\_\_\_\_ Dr's Phone #: \_\_\_\_\_  
 Type of Screen Refused: ☐ Newborn Blood Spot ☐ Pulse Oximetry Screen ☐ Hearing Screen  
 (check any that apply & complete the corresponding section(s) below)

I, (Guardian's name) \_\_\_\_\_, have been fully informed of the importance of newborn screening, and I understand that all newborns are required by law\* to have the newborn screening tests performed. Although the benefits of newborn screening and the dangers of not being screened have been explained to me, I elect to refuse the newborn screening test(s) checked above for my child, (Infant's name) \_\_\_\_\_, born on \_\_\_\_/\_\_\_\_/\_\_\_\_, as such testing of my infant conflicts with my religious tenets and practices. My decision was made freely, and I accept the legal responsibility for the consequences of this decision. I have discussed the newborn screening tests with \_\_\_\_\_, my child's healthcare provider, and I understand the risks to my child if the newborn screen(s) are not completed.

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**Blood Spot Refusal**  
 I, (Guardian's name) \_\_\_\_\_, understand the disorders included in the newborn metabolic screen test are easily detected by testing a small blood sample from my baby's heel. I am aware that the signs and symptoms of these disorders sometimes do not appear for several weeks or months, and irreversible damage can occur before symptoms become apparent. I have been informed that these conditions are treatable but if left untreated may cause permanent damage to my child, including mental retardation, growth failure, and even death. I also understand that my current declination does not prevent me from later changing my mind and that a blood spot screen can be performed up to 6 months of age.

---

**Pulse Oximetry Refusal**  
 I, (Guardian's name) \_\_\_\_\_, understand the congenital heart defects that the pulse oximetry test screen for can be detected by measuring the amount of oxygen in my baby's blood. I am aware that the signs and symptoms of these defects sometimes do not appear for several weeks or months, and irreversible damage or death can occur if not identified early.

---

**Hearing Refusal**  
 I, (Guardian's name) \_\_\_\_\_, understand the importance of finding out if my baby can hear sounds needed to listen and talk. It has been explained to me that most babies born with hearing loss have parents who can hear and there is no history of hearing loss in their family. I understand that any degree of hearing loss has the potential to interrupt speech, language, cognition, emotional and/or social development. I also understand that my current declination does not prevent me from changing my mind. I also understand that a hearing screen can be performed on my child at any time I choose.

---

Print Parent/legal Guardian's Name \_\_\_\_\_ Signature of Parent/Legal Guardian \_\_\_\_\_ Date \_\_\_\_/\_\_\_\_/\_\_\_\_  
 Print Witness Name \_\_\_\_\_ Signature of Witness \_\_\_\_\_ Date \_\_\_\_/\_\_\_\_/\_\_\_\_

\*63 O.S. §§ 1-533, 1-534; & 1-543 (2025)

Directions:  
Original Copy to Infant's record  
Provide copy to parent and healthcare provider  
Attach to the blood spot demographic form and send to the Public Health Laboratory or facsimile/email a copy to the Newborn Screening Program Coordinator:

Oklahoma State Department of Health  
(405) 426-8000 • (800) 522-0203 • Oklahoma.gov/Health

Oklahoma State Department of Health  
Newborn Screening Program Coordinator  
123 Robert S. Kerr Ave Ste 1702  
Oklahoma City, OK 73102-6406  
Fax (405) 900-7596  
Email: NewbornScreen@health.ok.gov  
Phone (405) 462-8310 or 1-800-766-2223



# Filling Out the Demographic Form

# Which Babies Do Not Need a Demographic Form Submitted?

- Babies who are stillborn and will not have a birth certificate issued do not need to have a demographic form submitted.

Every other baby born needs to have a demographic form submitted.

- **Born alive and expire** before the 24-hour collection time – complete demographic form and **submit without bloodspots** to the Public Health Lab along with other specimens. Mark Expired box and provide date.
- **Transferred** prior to collection time. Complete demographic form and mark Transfer box, providing name of receiving hospital, **submit to PHL without bloodspots**.
- **Refusal**. Complete demographic form, mark Refusal box, and **submit to PHL without bloodspots**. Include copy of signed refusal form with demographic form.



# Filling out the Form

**1899064**  **Oklahoma Newborn Screening (NBS) Form** **DO NOT WRITE HERE**  
To order forms, call the OSDH NBS Program (405) 271-5070

☐ First Screen ☐ Repeat Screen ☐ Previous NBS Lab# \_\_\_\_\_

Not Screened Due To ☐ Refused ☐ Expired \_\_\_\_/\_\_\_\_/\_\_\_\_ Tests Requested ☐ All Tests  
☐ Transferred \_\_\_\_/\_\_\_\_/\_\_\_\_ to \_\_\_\_\_ ☐ HGB Only ☐ GALT  
☐ Phe Monitor ☐ CFTR

**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

**MOTHER'S/GUARDIAN'S INFORMATION**

☐ DHS Custody ☐ 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 # \_\_\_\_\_

**MEDICAL/FEEDING HISTORY (Check all that apply)**

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

**PULSE OXIMETRY/CCHD SCREEN**

☐ Pass ☐ Fail ☐ Not Performed ☐ Refused ☐ Echo

**HEARING SCREEN**

Do not write in this box

Date of Final Screen \_\_\_\_/\_\_\_\_/\_\_\_\_ Right Ear: ☐ Pass ☐ Refer Left Ear: ☐ Pass ☐ Refer

Screen Method ☐ ABR ☐ OAE

If not screened, reason  
☐ Delayed ☐ Discharged ☐ No Supplies ☐ Refused ☐ Technical Problem

Hearing Risk Status (Select all that apply)  
☐ Family History ☐ In Utero Infection ☐ Craniofacial Anomalies ☐ ECMO ☐ Both Hyperbilirubinemia AND Exchange Transfusion ☐ NICU

**SUBMITTER'S INFORMATION**

Submitting Facility's/Provider's ID # \_\_\_\_\_

Submitter's Name/Address \_\_\_\_\_

**CHART COPY**  
DETACH AND PLACE IN MEDICAL RECORD

**DETACH AND GIVE TO PARENT OR GUARDIAN**

**DETACH AND GIVE TO PARENT OR GUARDIAN**

Use black or blue ink ball point pen only.  
See full instructions for completion of form on back page.

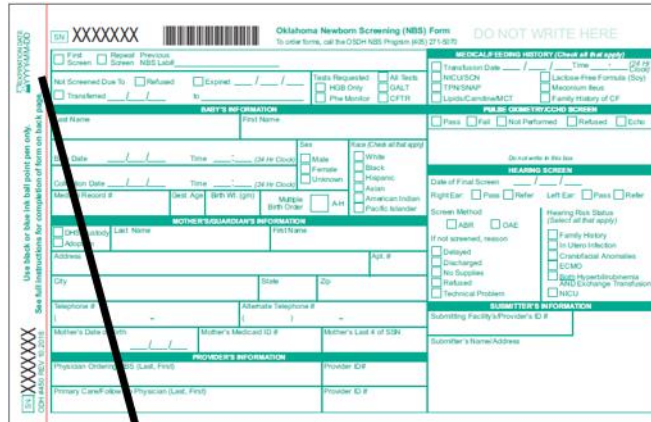
**1899064**  
ODH #450 REV 04.2019

Specimen testing may be delayed if the form is incomplete!

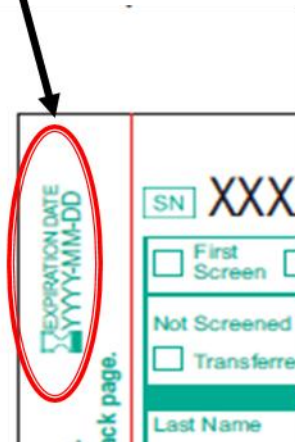


# Filling out the Form

Specimen testing will be delayed if the form is incomplete!



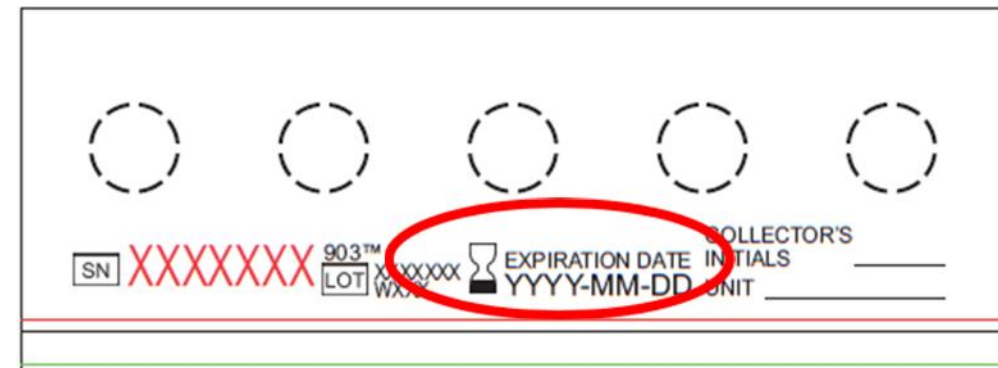
The image shows the top portion of the Oklahoma Newborn Screening (NBS) Form. It includes fields for the provider's name, address, and contact information. There are also checkboxes for 'First Screen', 'Not Screened', and 'Transferred'. A red circle highlights the 'EXPIRATION DATE' field, which is labeled 'YYYY-MM-DD'.



A close-up view of the 'EXPIRATION DATE' field on the form. The field is labeled 'EXPIRATION DATE' and 'YYYY-MM-DD'. A red circle highlights the field, and a black arrow points from the top form to this close-up.

- **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.



The image shows a close-up of the filter paper kit. It features five circular punch holes at the top. Below the holes, there is a section for the 'EXPIRATION DATE' labeled 'YYYY-MM-DD'. A red circle highlights the expiration date field. To the right of the expiration date field, there is a section for the 'COLLECTOR'S INITIALS' and 'UNIT'.



# 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 'First Screen' box in the 'Specimen Information' section. A black arrow points from this circle to a zoomed-in view of the same section on the right.

- 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 you have it.

If you don't mark “repeat screen” the correct linking to the original screen could be delayed.

This is a zoomed-in view of the 'Specimen Information' section of the Oklahoma NBS form. A red circle highlights the 'First Screen' and 'Repeat Screen' boxes. The 'First Screen' box is checked, and the 'Repeat Screen' box is unchecked. The 'Previous NBS Lab#' field is empty.



# 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 under the 'Not Screened Due To' section. A black arrow points from this circle to a zoomed-in view of the same section on the right.

- 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 'Not Screened Due To' section of the Oklahoma Newborn Screening (NBS) form. The 'Expired' checkbox is circled in red, and the date fields next to it are visible. The section also includes checkboxes for 'First Screen', 'Repeat Screen', 'Previous NBS Lab#', 'Refused', and 'Transferred'.



# 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 under the 'Not Screened Due To' section. A large black arrow points from this circle to a zoomed-in view of the same section on the right.

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 'Not Screened Due To' section of the Oklahoma NBS form. A red circle highlights the 'Transferred' checkbox and the date field. The form also shows the 'Tests Requested' section with checkboxes for 'HGB Only', 'Phe Monitor', 'All Tests', 'GALT', 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 in the top right corner. A large black arrow points from this section to a zoomed-in view of the same section in the image below.

This is a zoomed-in view of the 'Tests Requested' section of the Oklahoma Newborn Screening (NBS) form. A red circle highlights the section, which includes checkboxes for 'All Tests', 'HGB Only', 'GALT', 'Phe Monitor', and 'CFTR'. The 'Tests Requested' label is also circled in red.

- Tests Requested: Check all that apply.
  - **All Tests**- always check unless test is for HGB only. This ensures that the lab screens for all disorders on the NBS panel.
  - **HGB Only**- Check if the repeat screen is for a follow-up of the 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.
  - **CFTR**- Check in addition to All Tests if baby has clinical concerns for CF, meconium ileus, and/or family history of CF.
  - **Phe Monitor** – Used by geneticists only.



# Filling out the Form: Infant's Information – Initial screen

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. A black arrow points from this section to a zoomed-in view of the same section on the right.

- 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.

This is a zoomed-in view of the 'BABY'S INFORMATION' section of the form. The 'Last Name' and 'First Name' fields are circled in red. Below these fields are sections for Birth Date, Time, Sex, Race, Collection Date, Time, Medical Record #, Gest. Age, Birth Wt. (gm), Multiple Birth Order, and 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 same section on the right.

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

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



# 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. A black arrow points from this section to a zoomed-in view of the same section on the right.

- Date & Time of birth
  - Enter the time using the **24-hour clock**. For example, 1PM would be entered as 13:00.
  - For a repeat screen, outside of hospital, if time is not known, this box can be left empty.

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



**Specimen testing will be delayed if the form is incomplete!**

**BABY'S INFORMATION**

First Name \_\_\_\_\_

Sex ☐ Male ☐ Female ☐ Unknown

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

Birth Date \_\_\_\_/\_\_\_\_/\_\_\_\_ Time \_\_\_\_:\_\_\_\_ (24 Hr Clock)

Collection Date \_\_\_\_/\_\_\_\_/\_\_\_\_ Time \_\_\_\_:\_\_\_\_ (24 Hr Clock)

Medical Record # \_\_\_\_\_ Gest. Age \_\_\_\_\_ Birth Wt. (gms) \_\_\_\_\_

Multiple Birth Order ☐ A/R ☐

**WOMEN'S/GUARDIAN'S INFORMATION**

☐ DHS Custody ☐ Adoption

Last Name \_\_\_\_\_

Address \_\_\_\_\_ Apt. # \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone # (\_\_\_\_) \_\_\_\_\_-\_\_\_\_ Adorable 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 # \_\_\_\_\_

**PALM GEOMETRY/CHD SCREEN**

Pass ☐ Fail ☐ Not Performed ☐ Refused ☐ Echo ☐

**HEARING SCREEN**

Do not write in this box

Date of Hearing Screen \_\_\_\_/\_\_\_\_/\_\_\_\_

Right Ear: ☐ Pass ☐ Refer ☐ Left Ear: ☐ Pass ☐ Refer ☐

Screen Method (Select all that apply)  
☐ ASR ☐ OAE

Reason for referral (Select all that apply)  
☐ Family History ☐ In Utero Infection ☐ Craniofacial Anomalies ☐ ECMO ☐ No Supplies ☐ Refused ☐ Suspected Hyperbilirubinemia ☐ AND Exchange Transfusion ☐ NICU ☐ Technical Problem

**SUBMITTER INFORMATION**

Submitting Facility's/Provider's Name/Address \_\_\_\_\_

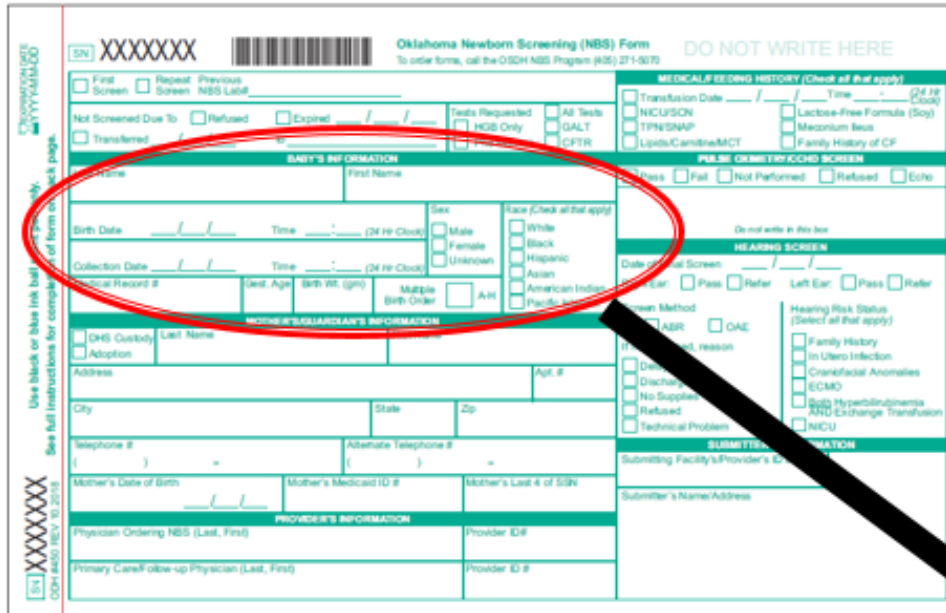
Submitter's Name/Address \_\_\_\_\_

- Ideal time for well, term newborn:  
*24 hours + 1 minute of age*

Collection Date \_\_\_\_/\_\_\_\_/\_\_\_\_ Time \_\_\_\_:\_\_\_\_ (24 Hr Clock)

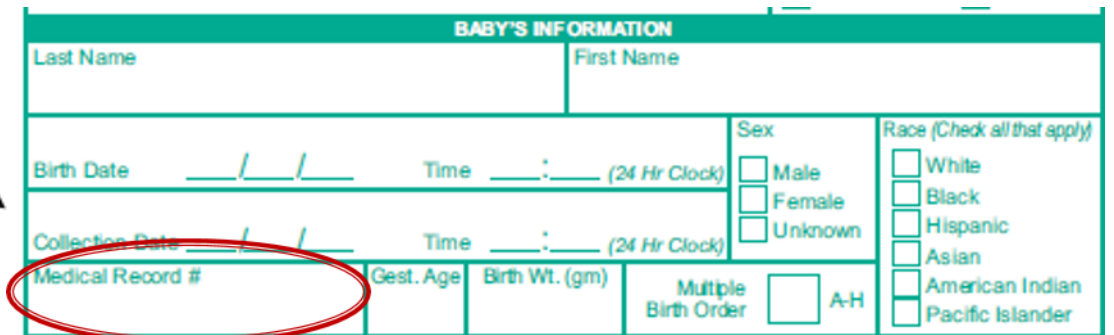
# Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!



The image shows the Oklahoma Newborn Screening (NBS) Form. A red oval 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 same section on the right.

- Medical record number
  - Baby's medical record number
  - If a multiple birth, take extreme care here



This is a zoomed-in view of the 'BABY'S INFORMATION' section of the form. It 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. The 'Medical Record #' field is circled in red.



# 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 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. An arrow points from this section to a zoomed-in view of the same section on the right.

- Gestational Age
  - List gestational age at birth, may leave blank on a repeat collection.
  - Lab cut off values for abnormal severe combined immunodeficiency (SCID) are gestational age dependent.

This is a zoomed-in view of the 'BABY'S INFORMATION' section of the Oklahoma Newborn Screening (NBS) Form. It 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. The 'Gest. Age' field is circled in red.



# Filling out the Form: Infant's Information

Specimen testing will be delayed if the form is incomplete!

The image shows a portion 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), leave blank if unknown (for repeat screen out of hospital).
- Lab cut off values for abnormal congenital adrenal hyperplasia (CAH) results are dependent on birth weight.

This is a zoomed-in view of the 'BABY'S INFORMATION' section of the form. It contains the following fields:

| BABY'S INFORMATION             |           |                              |                                                                                                                                                                                                                                                                 |
|--------------------------------|-----------|------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Last Name                      |           | First Name                   |                                                                                                                                                                                                                                                                 |
| Birth Date ____/____/____      |           | Time ____:____ (24 Hr Clock) | Sex<br><input type="checkbox"/> Male<br><input type="checkbox"/> Female<br><input type="checkbox"/> Unknown                                                                                                                                                     |
| Collection Date ____/____/____ |           | Time ____:____ (24 Hr Clock) | Race (Check all that apply)<br><input type="checkbox"/> White<br><input type="checkbox"/> Black<br><input type="checkbox"/> Hispanic<br><input type="checkbox"/> Asian<br><input type="checkbox"/> American Indian<br><input type="checkbox"/> Pacific Islander |
| 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 screenshot of the 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 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.

This is a zoomed-in view of the 'BABY'S INFORMATION' section of the form. It 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. The 'Multiple Birth Order' field is circled in red, showing a box for 'A-H'.



# Filling out the Form: Mom's Information

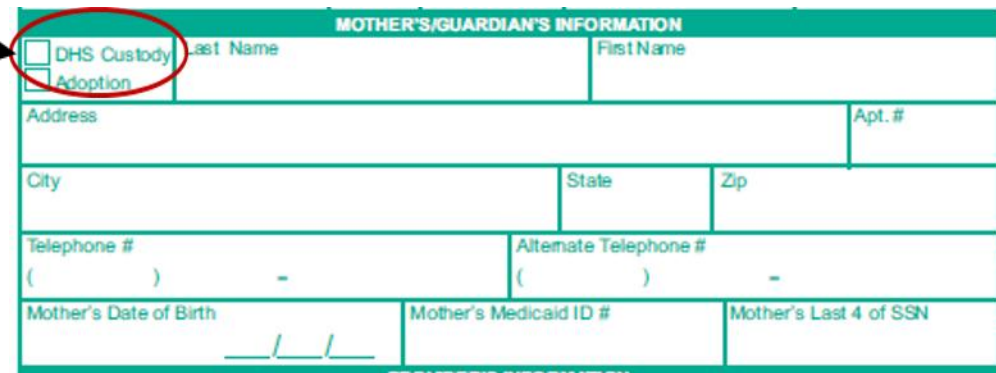
Specimen testing will be delayed if the form is incomplete!



The image shows the Oklahoma Newborn Screening (NBS) Form. A red circle highlights the 'MOTHER'S/GUARDIAN'S INFORMATION' section, which includes fields for Last Name, First Name, Birth Date, Time, Sex, Race, Address, City, State, Zip, Telephone #, Alternate Telephone #, Mother's Date of Birth, Mother's Medicaid ID #, and Mother's Last 4 of SSN. An arrow points from this section to a larger, detailed view of the same section on the right.

- DHS Custody or Adoption
- What About Surrogacy?

**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.



This is a detailed view of the 'MOTHER'S/GUARDIAN'S INFORMATION' section. It includes checkboxes for 'DHS Custody' and 'Adoption'. The form fields are: Last Name, First Name, Address, Apt. #, City, State, Zip, Telephone #, Alternate Telephone #, Mother's Date of Birth, Mother's Medicaid ID #, and Mother's Last 4 of SSN.



## Birth Mother – When to Omit/Protect Her Identity?

| Birth/Social Scenario | Who to List as Parent/Guardian       |
|-----------------------|--------------------------------------|
| Adoption              | Agency caseworker or adoptive parent |
| DHS Custody/Concern   | DHS caseworker                       |
| Surrogacy             | Adoptive parent                      |

- Birth mother's name does NOT belong on filter paper in these scenarios.
- **Potential pitfalls** include **pre-filling** the demographic form by an employee not aware of all social situations.
- This requires careful review by the collector, with ultimate review by the assigned nurse.



# Filling out the Form: Mom'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 'MOTHER'S/GUARDIAN'S INFORMATION' section. A black arrow points from this section to a zoomed-in 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 zoomed-in view of the 'MOTHER'S/GUARDIAN'S INFORMATION' section of the form. Red circles highlight the following fields: Last Name, First Name, Address, City, State, Zip, Telephone #, and Alternate Telephone #.



**Specimen testing will be delayed if the form is incomplete!**

- Physician Ordering the NBS:
  - Include first and last name
  - Enter the NBS Provider ID #, if known
  - May leave blank if ordering Physician unknown on a repeat collection, outside of hospital



# Filling out the Form: Provider's Information

## Specimen testing will be delayed if the form is incomplete!



The image shows the Oklahoma Newborn Screening (NBS) Form. A red oval highlights the 'PROVIDER'S INFORMATION' section at the bottom of the form. This section includes fields for 'Physician Ordering NBS (Last, First)' and 'Provider ID #', and 'Primary Care/Follow-up Physician (Last, First)' and 'Provider ID #'. An arrow points from this section to a zoomed-in view of the same section on the right.

- 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 # |



# Demographic Form – Details Make a Difference

This section is just for sick/NICU babies, RIGHT?  
NO! ALL NEWBORNS!

Lactose Free (Soy) Formula indicates an unreliable initial Galactosemia screen result, 2<sup>nd</sup> tier testing will need to be performed on this specimen. Please note any use of soy formula.

Meconium Ileus OR Family History of CF indicates automatic reflex to 2<sup>nd</sup> tier DNA level screen for CF.

**If we don't ask, we are missing these babies.... endless possible mutations for CF, family history earns baby a deeper investigation!**

Don't forget the Hearing Risk Status for well AND NICU babies. Note in utero infection, craniofacial anomalies, family history, etc. This triggers additional hearing screenings for these babies at risk for late onset loss.

**MEDICAL/FEEDING HISTORY (Check all that apply)**

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

**PULSE OXIMETRY/CCHD SCREEN**

☐ Pass ☐ Fail ☐ Not Performed ☐ Refused ☐ Echo

Do not write in this box

**HEARING SCREEN**

Date of Final Screen \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Right Ear: ☐ Pass ☐ Refer Left Ear: ☐ Pass ☐ Refer

Screen Method  
☐ ABR ☐ OAE

If not screened, reason  
☐ Delayed  
☐ Discharged  
☐ No Supplies  
☐ Refused  
☐ Technical Problem

**Hearing Risk Status (Select all that apply)**

☐ Family History  
☐ In Utero Infection  
☐ Craniofacial Anomalies  
☐ ECMO  
☐ Both Hyperbilirubinemia AND Exchange Transfusion  
☐ NICU



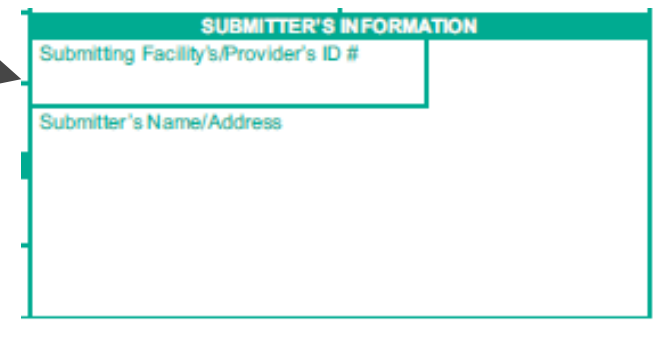
# Filling out the Form: Submitter ID

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, which is located at the bottom right of the form. This section contains fields for 'Submitting Facility's/Provider's ID #' and 'Submitter's Name/Address'.

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



This is a zoomed-in view of the 'SUBMITTER'S INFORMATION' section. It shows two fields: 'Submitting Facility's/Provider's ID #' and 'Submitter's Name/Address'.



# Filling out the Form: Collector's Initials

## Allows for thorough follow-up of an unsatisfactory screen

The diagram shows a rectangular form with five dashed circles at the top. Below the circles, there are several fields: 'SN' followed by 'XXXXXXXX', '903™ LOT' followed by 'XXXXXX', and 'EXPIRATION DATE' followed by 'YYYY-MM-DD'. To the right of these fields is a section labeled 'COLLECTOR'S' with two lines for 'INITIALS' and 'UNIT'. This section is circled in red.

**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.

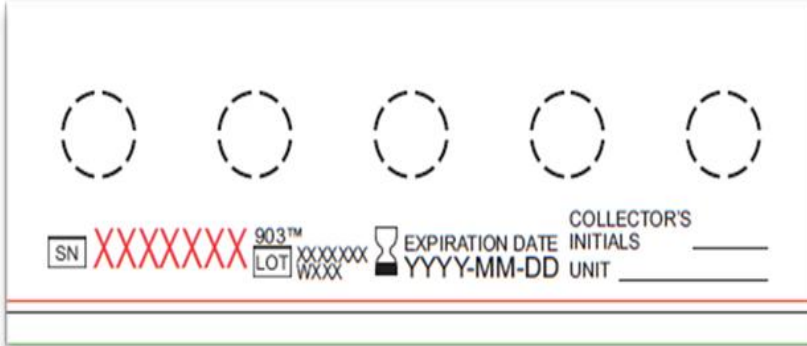


# Collecting the Specimen

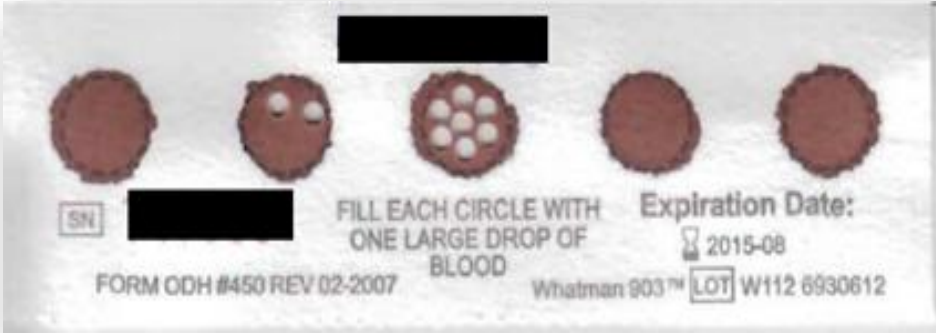


# How Is An Infant Screened?

- Blood spot screen-heel stick
- Performed when the infant is “24 hours plus one minute” or prior to discharge, whichever comes first
- A small amount of blood is placed on a small card and sent to the OSDH Newborn Screen lab.
- Newborn screening specimens are picked up from birthing hospitals and county health department via a contract courier service and then brought to the PHL for testing.



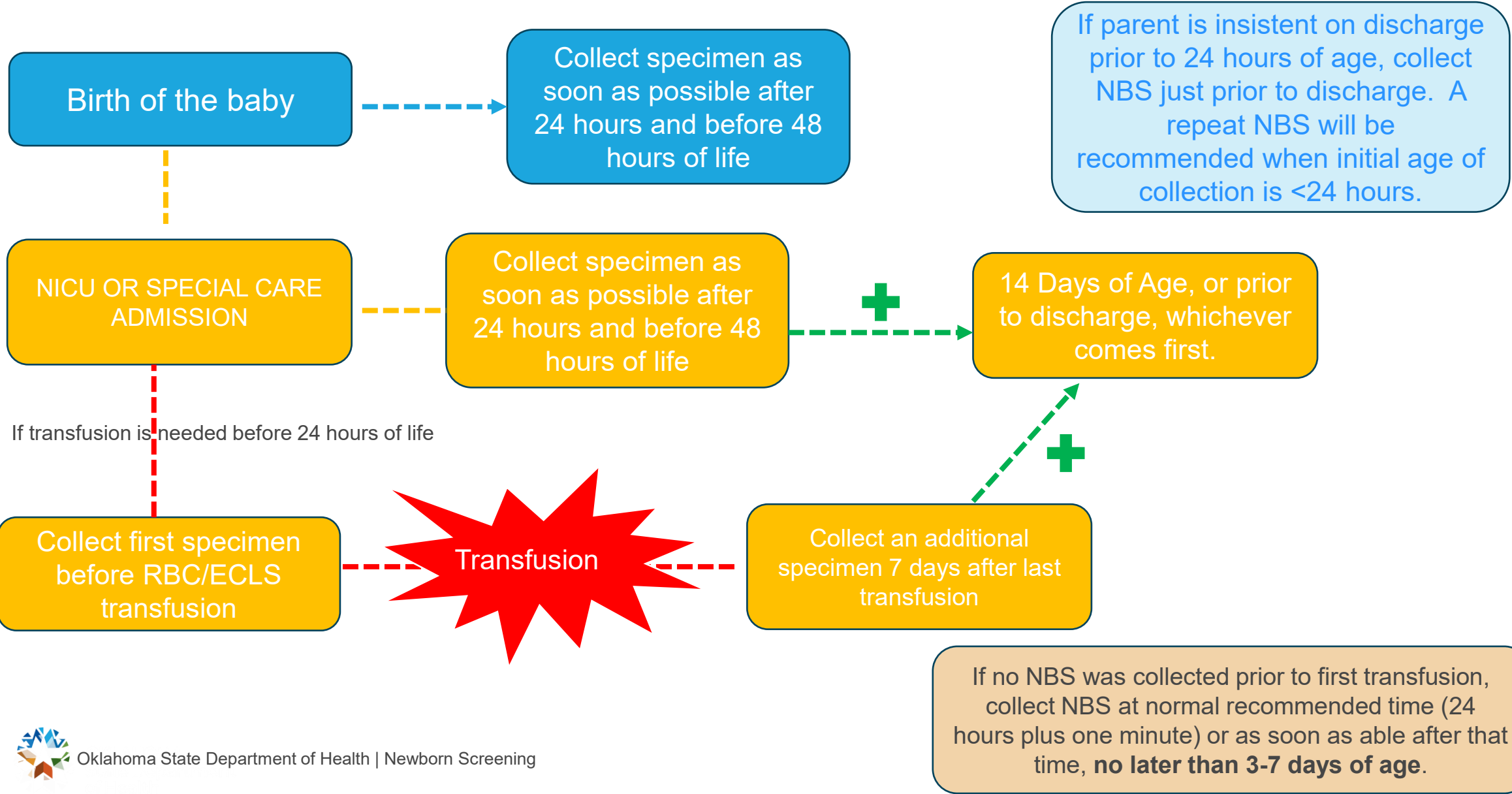
A blank newborn screening card template. It features five dashed circles at the top for blood spots. Below them, on the left, is a box for 'SN' followed by 'XXXXXXXX' and a box for 'LOT' followed by '903™ WXXX'. In the center, there is an 'EXPIRATION DATE' field with 'YYYY-MM-DD' and a box for 'INITIALS'. On the right, there is a box for 'COLLECTOR'S UNIT'. The card has a red and green border at the bottom.



A filled newborn screening card. It has five circles with blood spots. Below the circles, on the left, is a box for 'SN' followed by a blacked-out box. In the center, it says 'FILL EACH CIRCLE WITH ONE LARGE DROP OF BLOOD'. On the right, it says 'Expiration Date: 2015-08'. At the bottom, it says 'FORM ODH #450 REV 02-2007' and 'Whatman 903™ LOT W112 6930612'.

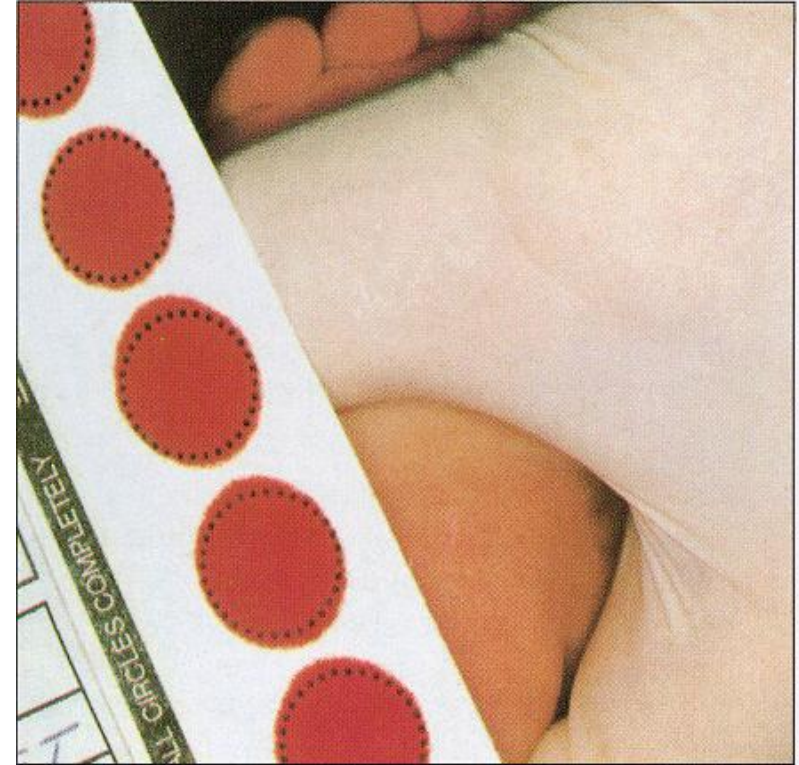


# Optimal Time of Bloodspot Collection – Well Baby and NICU



# Specimen Collection

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



# Direct Application

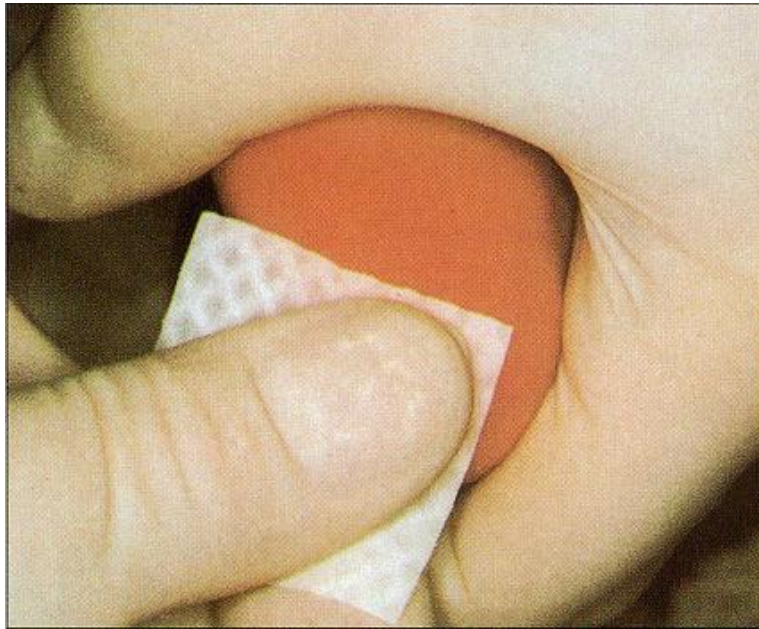


## Prepare the Site

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



# Direct Application

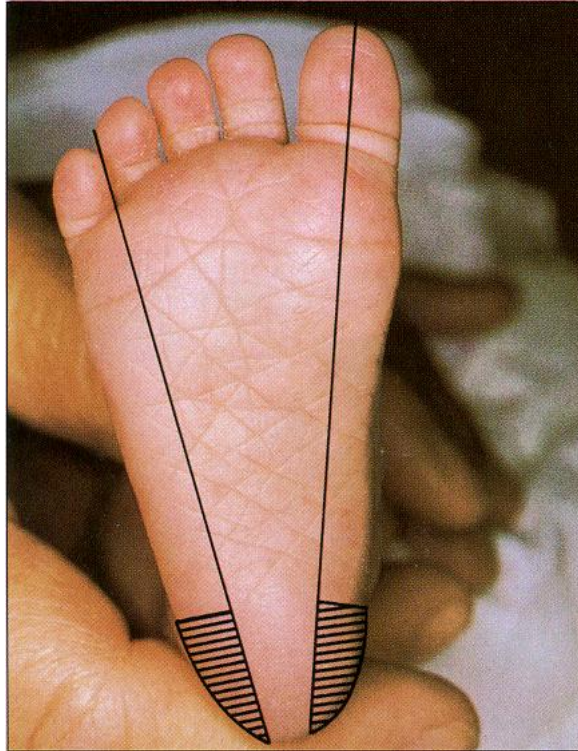


## Prepare the Site

- If desired, parent may hold infant during 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 unsatisfactory specimens.



# Direct Application

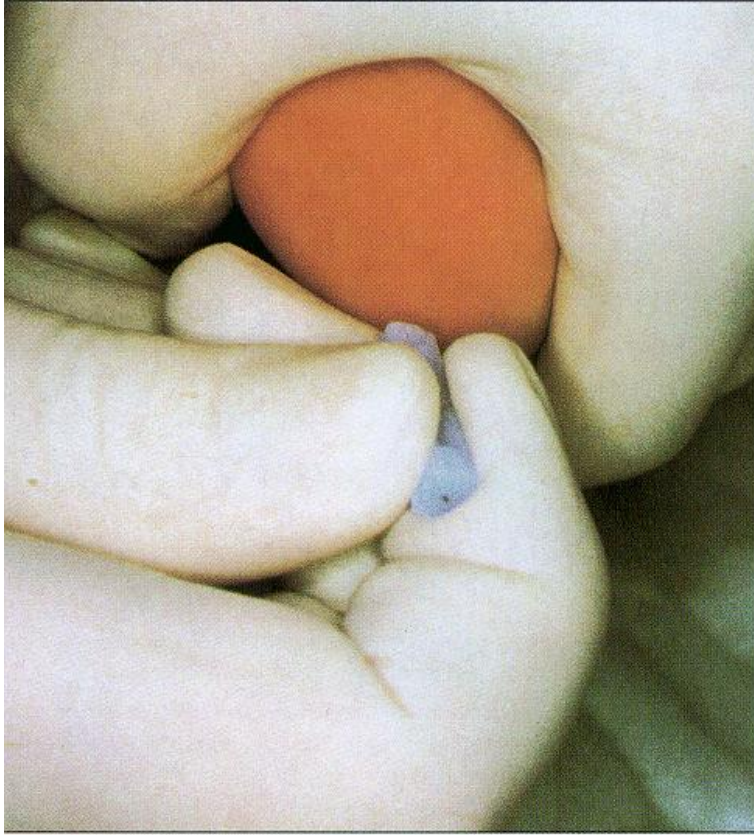


## Lancet Placement

- 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

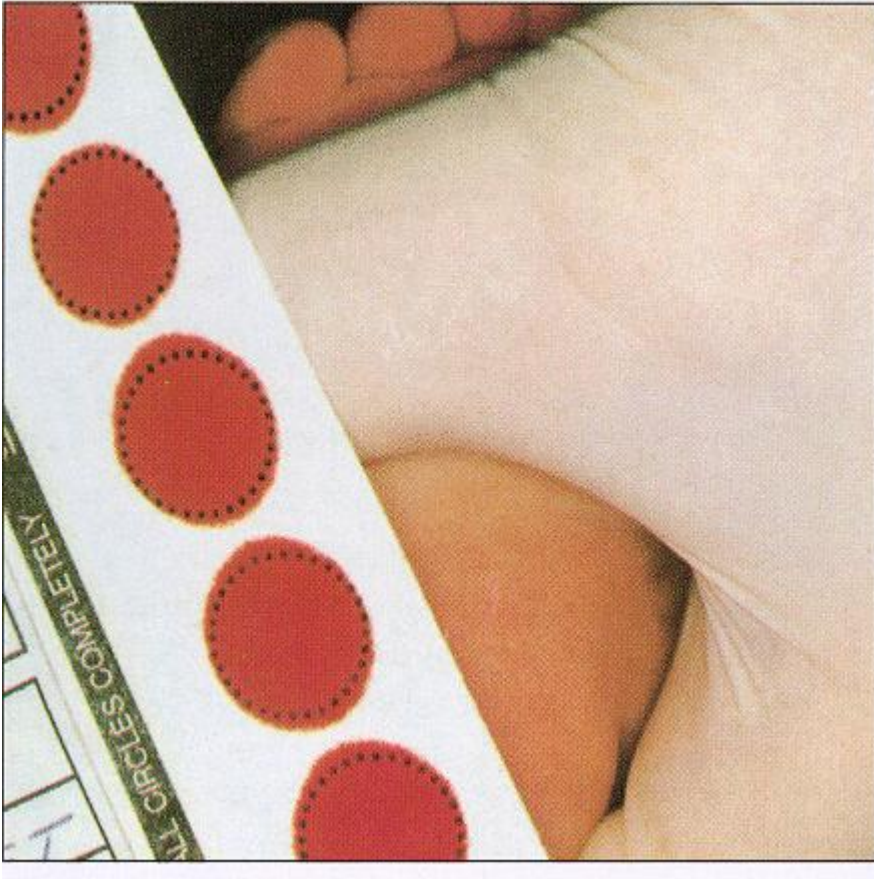


## Perform the Puncture

- 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

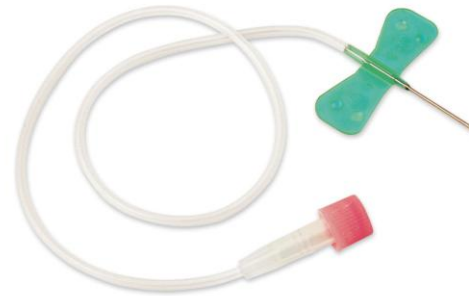
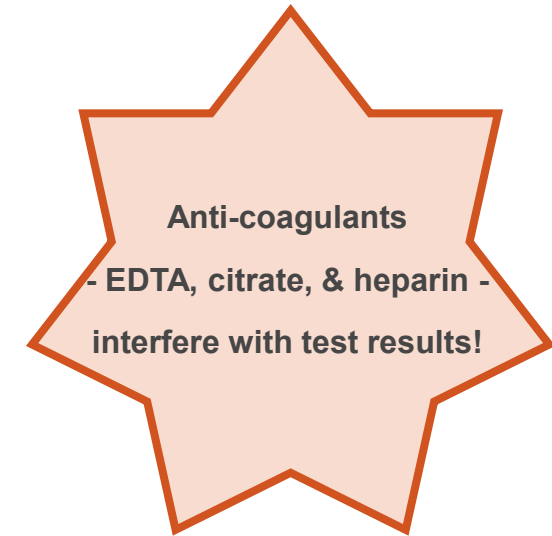
Gently touch the filter paper card to the blood drop and fill each printed circle with **one** large drop of blood.

- 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
- **What about venous samples?** >> Discouraged
- **What about umbilical catheters?** >> Discouraged
- **What about umbilical cord blood?** >> Discouraged



Only in certain circumstances (e.g., NICU)

Ensure the line is cleared by withdrawing 2-2.5 cc (ml) of blood to collect a specimen for newborn screen.



# Specimen Collection: What to Do

- Warm the heel and WAIT 3-5 minutes. Swaddle baby. Elevate baby's head.
- After site prep with alcohol, air dry, perform heel stick and wipe away first drop of blood with clean gauze.
- Wait for good size blood drop to form, apply drop to paper, holding as the blood fills the circle. Blood should be equally visible on both sides of the filter paper.
- Apply ONE drop of blood to each printed circle.
- Hold filter paper kit carefully, avoiding touching the white filter paper space with gloved or bare hands.
- Inspect specimen for quality after completion and again after drying, preferably with two sets of eyes. If questionable, send that bloodspot and then recollect as soon as able.
- May add additional spot(s) of same size as printed circles. Spots may not overlap.
- Complete log-book carefully.
- Examine demographic information for completeness and accuracy.
- Take dry specimens to lab or packaging station as soon as they are dry.



Diagram of a newborn screening filter paper kit showing six dashed circles for blood spots. Below the circles is a form with the following fields:

- SN: XXXXXXXX
- LOT: XXXXXX
- EXPIRATION DATE: YYYY-MM-DD
- COLLECTOR'S INITIALS: \_\_\_\_\_

The EXPIRATION DATE field is circled in red.



# 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 and 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.

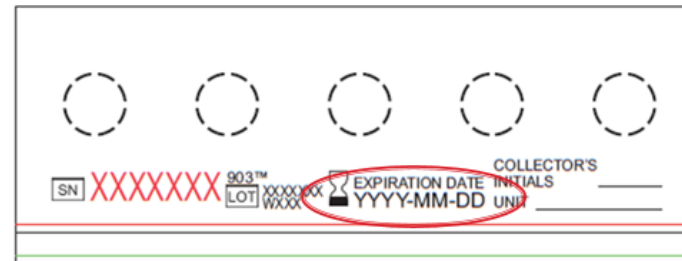


# Collection Reminders

## 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 and ensure screening results are received and recorded.**
- **Ensure that everybody who handles the filter paper or is involved in the newborn bloodspot collection process is trained.**

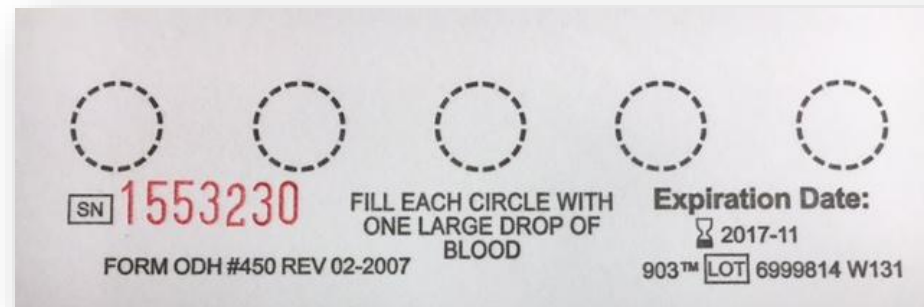


# NBS Filter Paper Review

## 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.



# Biggest Learning Curve – the Layered, Overlapping, or Clotted Sample Why Does This Matter?

(Flakes of glitter represent analytes in blood samples.)

## Single Layer Blood Spot

One layer of blood with appropriate ratio of analytes to standard punch volume



Newborn Screening Blood Spot

## Multi-layered Blood Spot

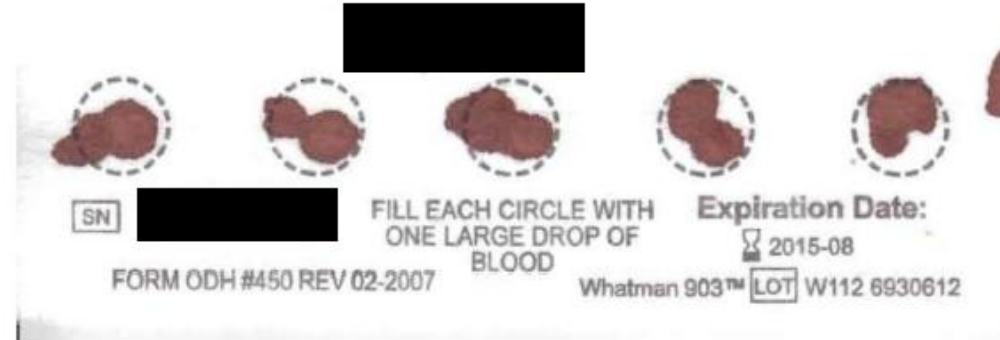
multiple layers of blood making ratio of analytes to standard punch volume much higher than expected.



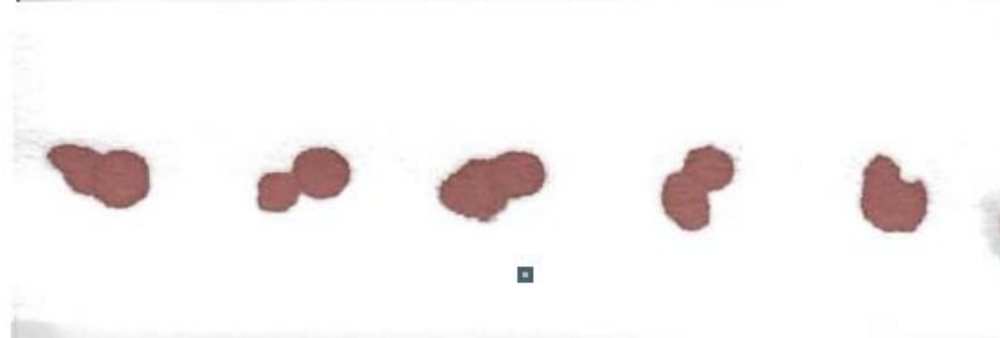
Newborn Screening Blood Spot

# 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



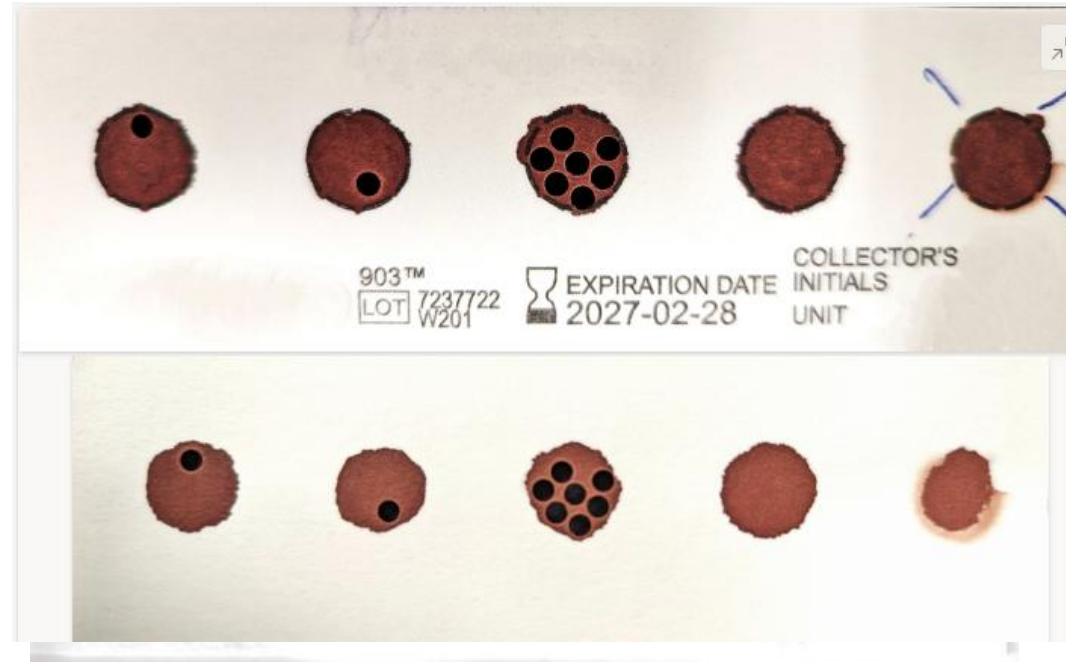
## *Why Unsat?*

- 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

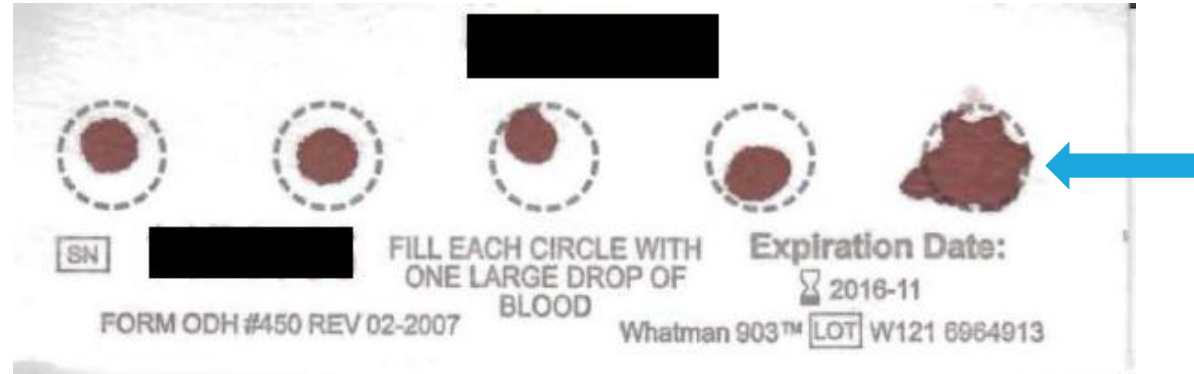
## *Why Unsat?*

- Notice the halos around the periphery of some of the pre-printed circles above. This can occur due to the following:
  - Insufficient drying of alcohol on the baby's heel prior to heel stick
  - 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

Front



Back



## *Why Unsat?*

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



# Under-Saturation

Front



Back

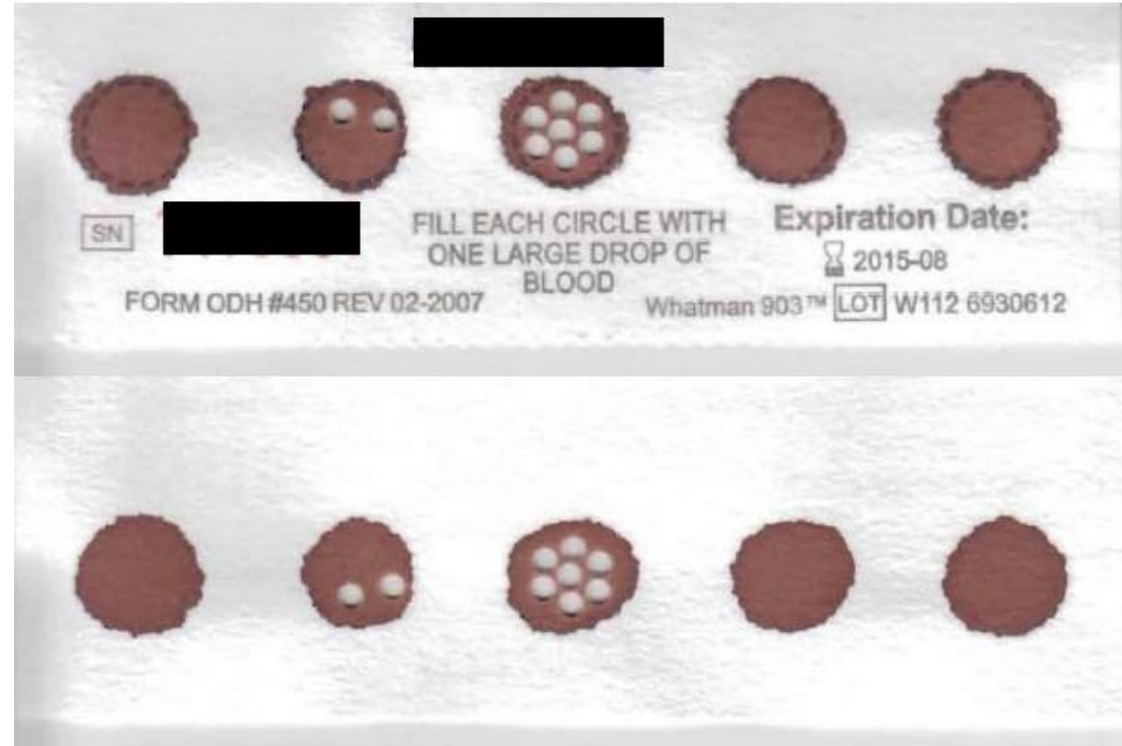
## *Why Unsat?*

- 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 Five Circles Needed?



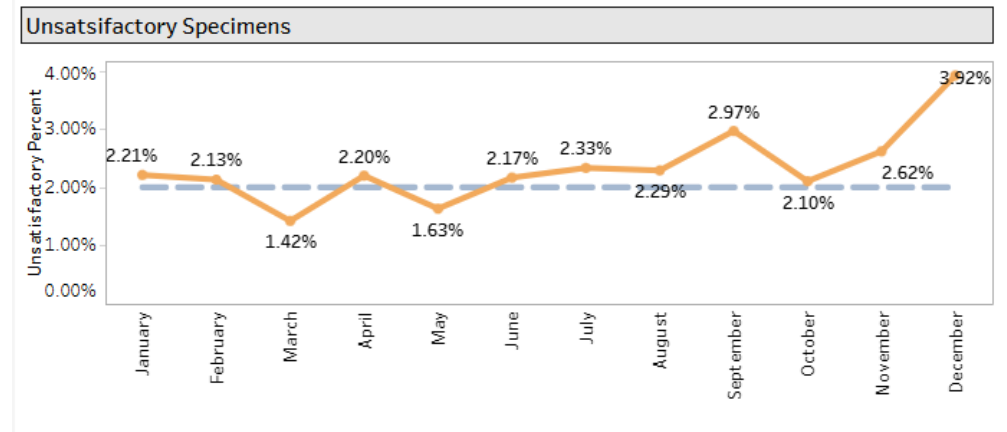
## Why?

- 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.
- Some samples will require a “2<sup>nd</sup> Tier test”, this calls for one of two of the spots to be shipped out of state to a reference lab for additional screening to determine risk for baby.
- Disorders will continue to be added to the newborn screening panel.



# What Happens to Babies with Unsatisfactory Screens?

**53,316 bloodspot specimens were submitted in 2025.  
1,246 of those were unsatisfactory for testing.  
2.34% unsatisfactory rate for the year, goal is <2.0%**



For the 1,246 unsatisfactory screens, the NBS Follow-Up team worked diligently to communicate with families and providers the importance of recollecting the NBS bloodspot sample.

## Unsatisfactory Screens in 2025 – Outcomes to Date

1,141 babies had unsatisfactory screens, some had more than one.

985 babies had repeat screens yielding normal results.

24 babies remain pending, two are with specialists.

120 babies did not have screens recollected, with bloodspot cases closed Unsatisfactory >>> Lost.

5 babies were diagnosed with disorders – TSH (2), SMA, POMPE and ASA.

5 babies were not recollected due to parent refusal.

2 babies passed away prior to recollection.



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



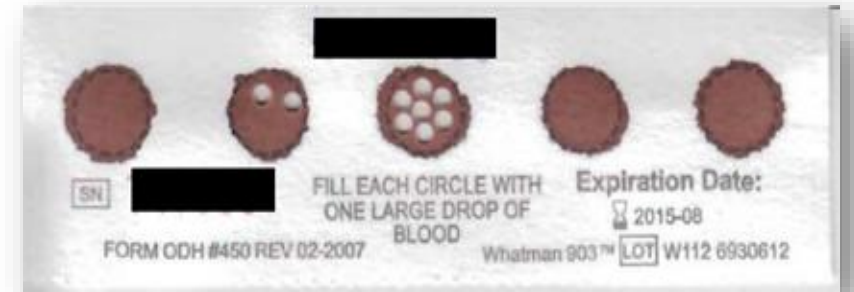
## “Practically Speaking.... How is that Consistently Possible?”

If a specimen is collected anytime (up to 11:59 PM) on “day one”, there is no reason that specimen can’t be dry, in the lab and ready for pick up on “day two”.

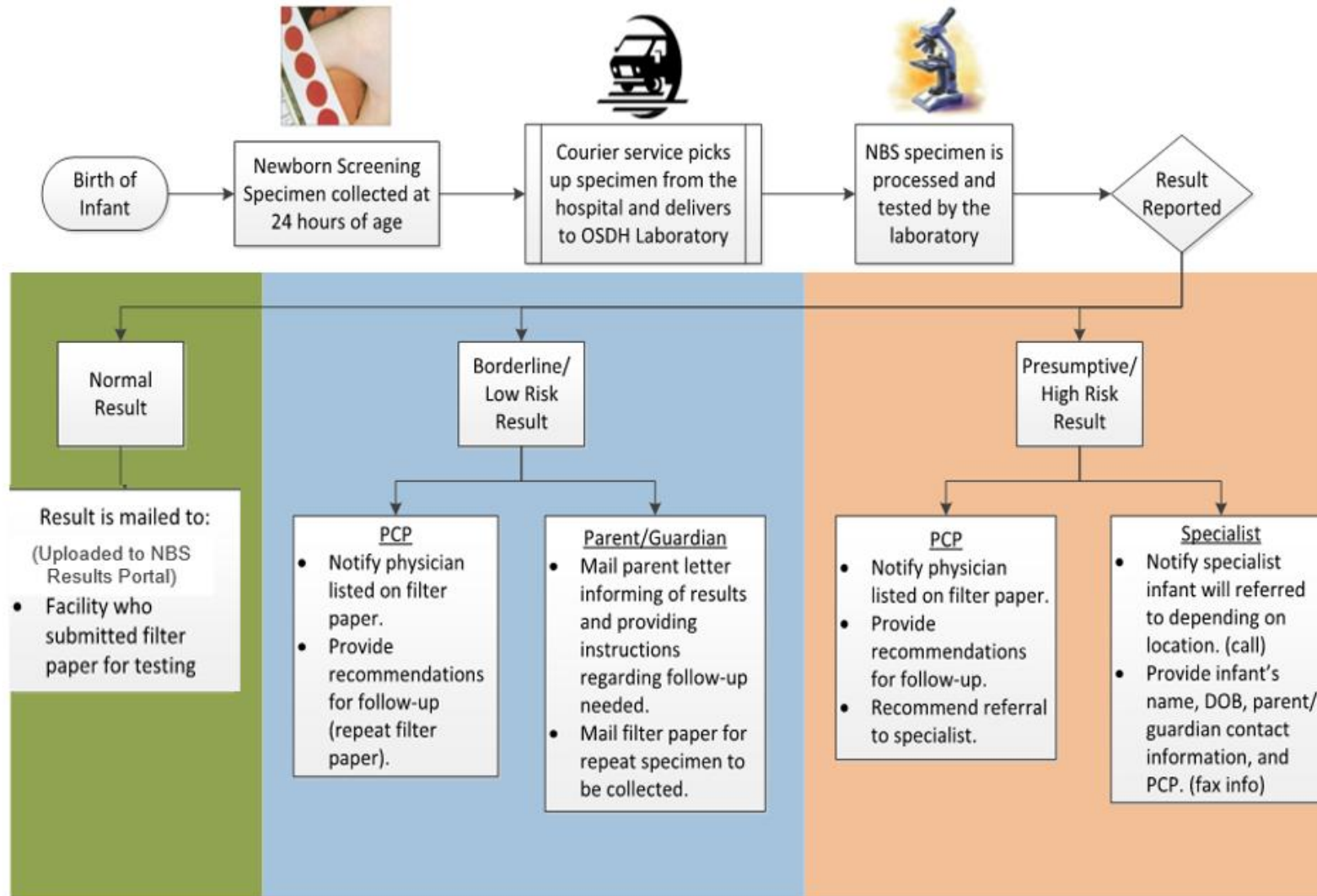
With every hospital having seven day a week courier service, every specimen should be able to arrive at the PHL the next day, regardless of the day of the week. The exception would be holidays or the very occasional weather-related delay.



# A Peek Inside the Laboratory....



# Blood Spot Screening is a system, not an event.



\*Short-term Follow-up continues tracking case until confirmed normal or diagnosed with a disorder.



# NICU Special Considerations

## Infant

- Prematurity and 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, and carnitine may affect amino acid, fatty acid, or organic acid results
- Steroids may affect 17-OHP results
- ECLS and 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



# Impact

# Diagnosed Cases – Preliminary Data 2025

Congenital Hypothyroidism - 64

Cystic Fibrosis – 28

BIO – 4

Pompe – 5

\*CIT/ASA – 3

SMA – 5

HGB – 5

PKU - 2

X-ALD – 3

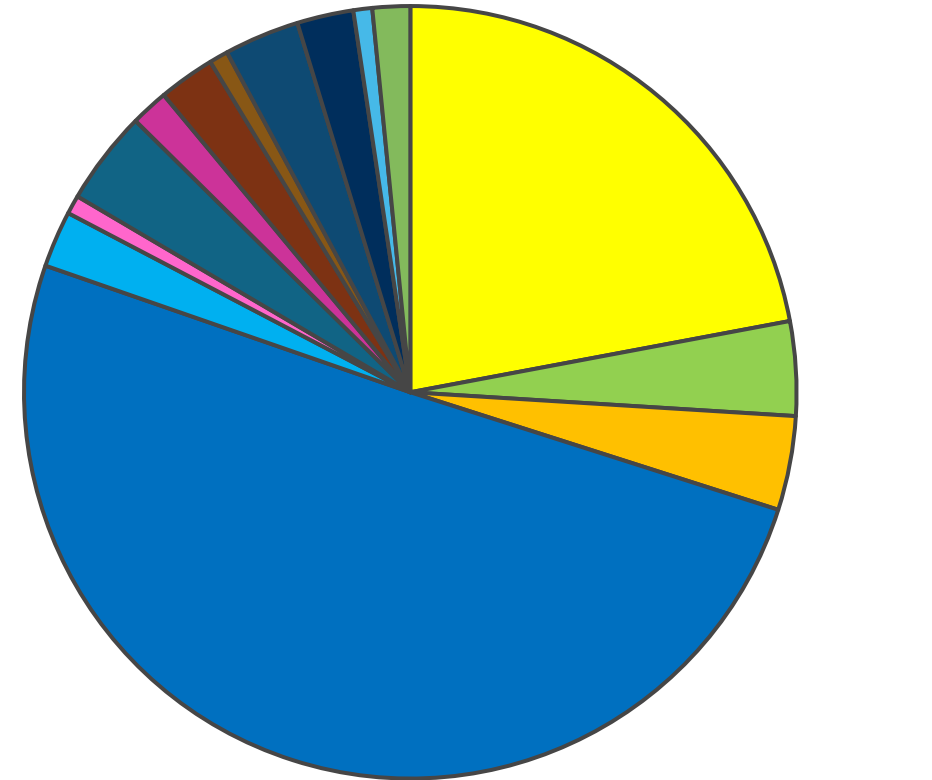
\*CAH – 3

\*VLCAD – 3

\*MCADD – 1

CUD – 1

\*GAL – 1



|                   |         |         |           |         |
|-------------------|---------|---------|-----------|---------|
| ■ Cystic Fibrosis | ■ Pompe | ■ SMA   | ■ CH      | ■ VLCAD |
| ■ MCADD           | ■ HGB   | ■ X-ALD | ■ CIT/ASA | ■ CUD   |
| ■ BIO             | ■ CAH   | ■ GAL   | ■ PKU     |         |

These **128** infant's screens were collected by **34** different submitters.



# Newborn Hearing Screening

# Why Newborn Hearing Screening is Important

Cannot  
always  
“see” a  
hearing  
loss

92% of  
children  
with  
hearing  
loss are  
born to  
hearing  
parents

$\frac{1}{2}$  of  
children  
identified  
with a  
hearing  
loss do not  
have a risk  
factor

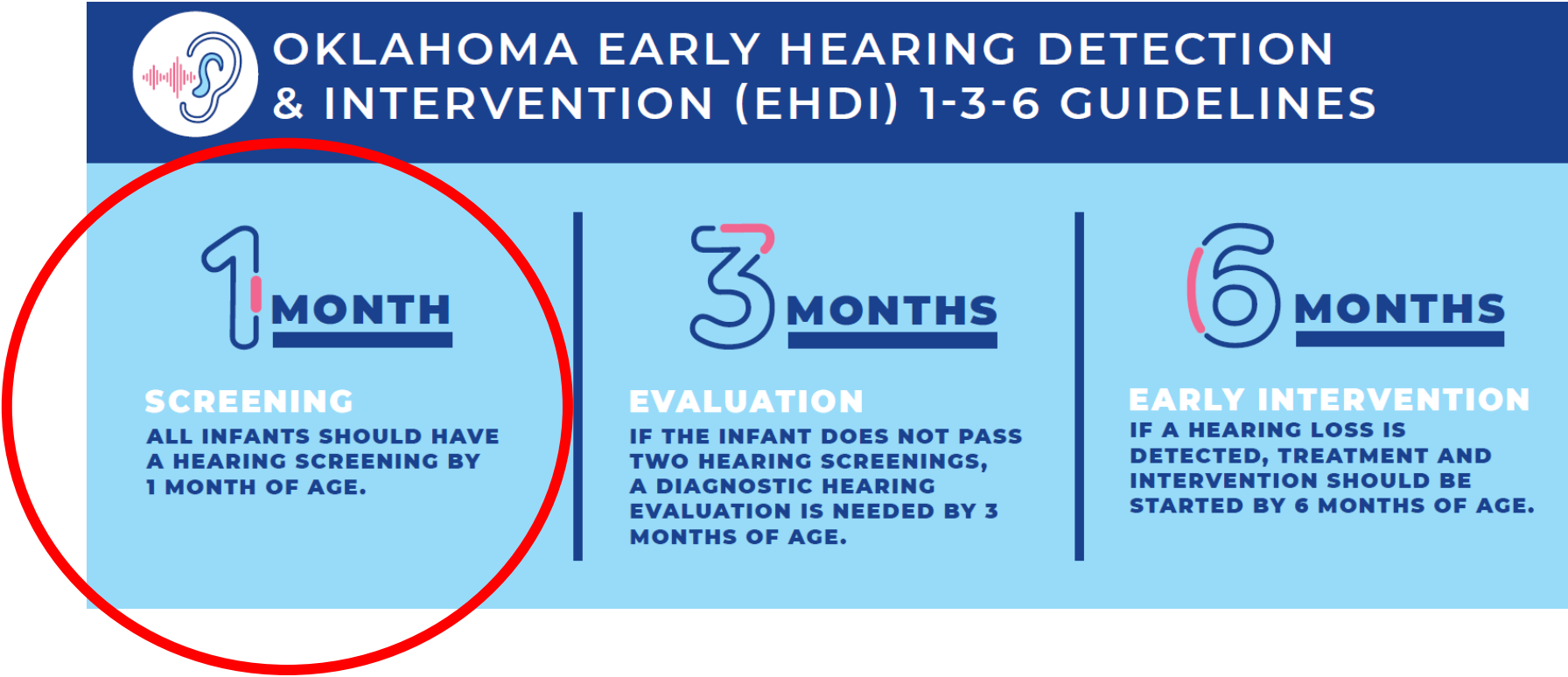
The  
prevalence of  
permanent  
hearing loss  
in 2022 was  
1.7 per 1,000  
births

A total of  
6,272 infants  
were  
diagnosed  
with  
permanent  
hearing loss  
in 2022  
following  
NBHS

[2022 Summary of National CDC EHDI Data](#) | [Annual Data EHDI Program](#) | [CDC](#)



# Newborn Hearing Screening



# Newborn Hearing Screening – When and How

- At least 34 weeks of age
- Close to discharge while still having time to rescreen if possible
- If needed, the second screening should *not* be immediately after the first screen – ideally it should be several hours later

## Two High Quality Screens

- Want a quiet environment
  - Can use a sign on the door or inside
  - Okay to ask people to step out/ turn the TV off/etc.



- Ensure the baby is relaxed
  - Sleeping
  - Quiet
  - Well Fed
  - Dry
  - Comfortable
- Swaddle can help
  - Helps them relax
  - Keeps hands away from equipment
- Can be done bedside
- Can be done while baby is held by family
- Can be done while nursing



# Risk factors for Hearing Loss

- Family history of childhood hearing loss
- NICU stay of longer than five days
- Hyperbilirubinemia with exchange transfusion
- Aminoglycoside administration for more than five days
- Asphyxia or Hypoxic Ischemic Encephalopathy
- Extracorporeal membrane oxygenation (ECMO)
- In utero infections (herpes, rubella, syphilis, toxoplasmosis)
- Congenital Cytomegalovirus (CMV)
- Caregiver Concern

- Maternal Zika, COVID-19
- Craniofacial abnormalities
- 400 Syndromes are associated with hearing loss
- Events associated with hearing loss (head trauma, fractures)
- Chemotherapy
- Not meeting speech and language milestones
- Balance difficulties (walking, changing surfaces)

Hearing Risk Status  
(Select all that apply)

|                                     |                                                     |
|-------------------------------------|-----------------------------------------------------|
| <input checked="" type="checkbox"/> | Family History                                      |
| <input type="checkbox"/>            | In Utero Infection                                  |
| <input type="checkbox"/>            | Craniofacial Anomalies                              |
| <input type="checkbox"/>            | ECMO                                                |
| <input type="checkbox"/>            | Both Hyperbilirubinemia<br>AND Exchange Transfusion |
| <input checked="" type="checkbox"/> | NICU                                                |



# Sharing Hearing Screen Results

- Make sure family understands results prior to discharge
- **Pass** – No follow-up needed unless concerns arise
- **Pass with risk** – Another screening at six months or as recommended by their provider
- **Refer** – Repeat screening or have a diagnostic test
- **Missed screening** – Complete a NBHS by one month of age

## Things to Say

- Did not pass / refer
- Does not mean there is a hearing loss
- Just means we need more testing
- Can do another screening or go to a pediatric audiologist

## Things to not Say

- It is just fluid
- It is our equipment /equipment is old
- I am sure it is nothing
- It was just loud



# Pulse Oximetry Screening

CCHD – Critical Congenital Heart Disease

# Critical Congenital Heart Disease (CCHD)

- Screening began in 2014.
- Screening is done by utilizing pulse-oximetry.
- Critical congenital heart defects are conditions that are present at birth and can affect the structure of a baby's heart and the way it works.



# 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.

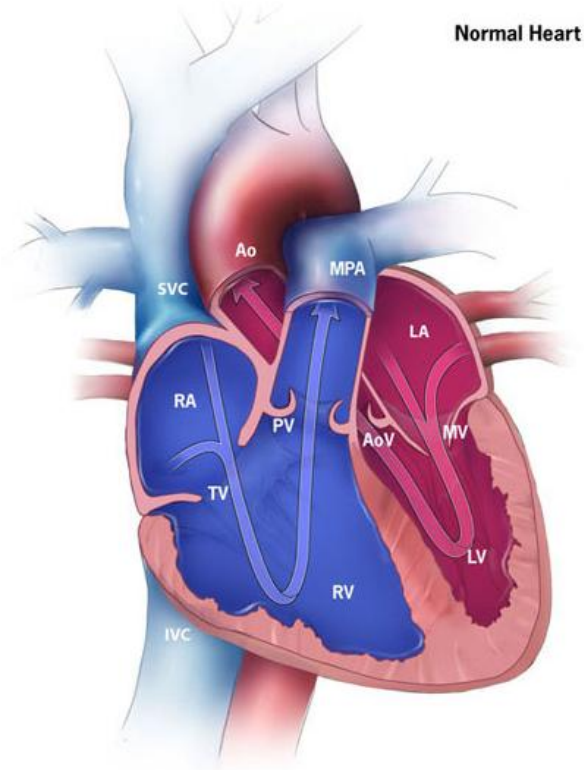


# Pulse-Oximetry Screening

- Simple and painless way to measure the amount of oxygen in the baby's blood.
- Congenital heart disease is the **most common** birth defect
- One in 110 infants will have a heart defect, 25% of those cases will have CCHD.
- Most affected will not have symptoms 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

- 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 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.

Image credit: CDC (2014)



# Why Screen Both Hand AND Foot in Newborn

- Right Hand (Pre-ductal): Measures blood oxygen levels BEFORE it passes through the ductus arteriosus (a temporary blood vessel connecting the aorta and the pulmonary artery in a fetus).
- Either Foot (Post-ductal): Measures blood oxygen levels AFTER the ductus arteriosus.
- Comparing the two helps doctors identify specific types of heart defects. In many CCHD cases, a difference in oxygen saturation between the hand and the foot (or a drop in both) indicates that oxygen-poor blood is mixing with oxygen-rich blood, or that the heart is struggling to pump oxygenated blood efficiently to the rest of the body.



# 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 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.



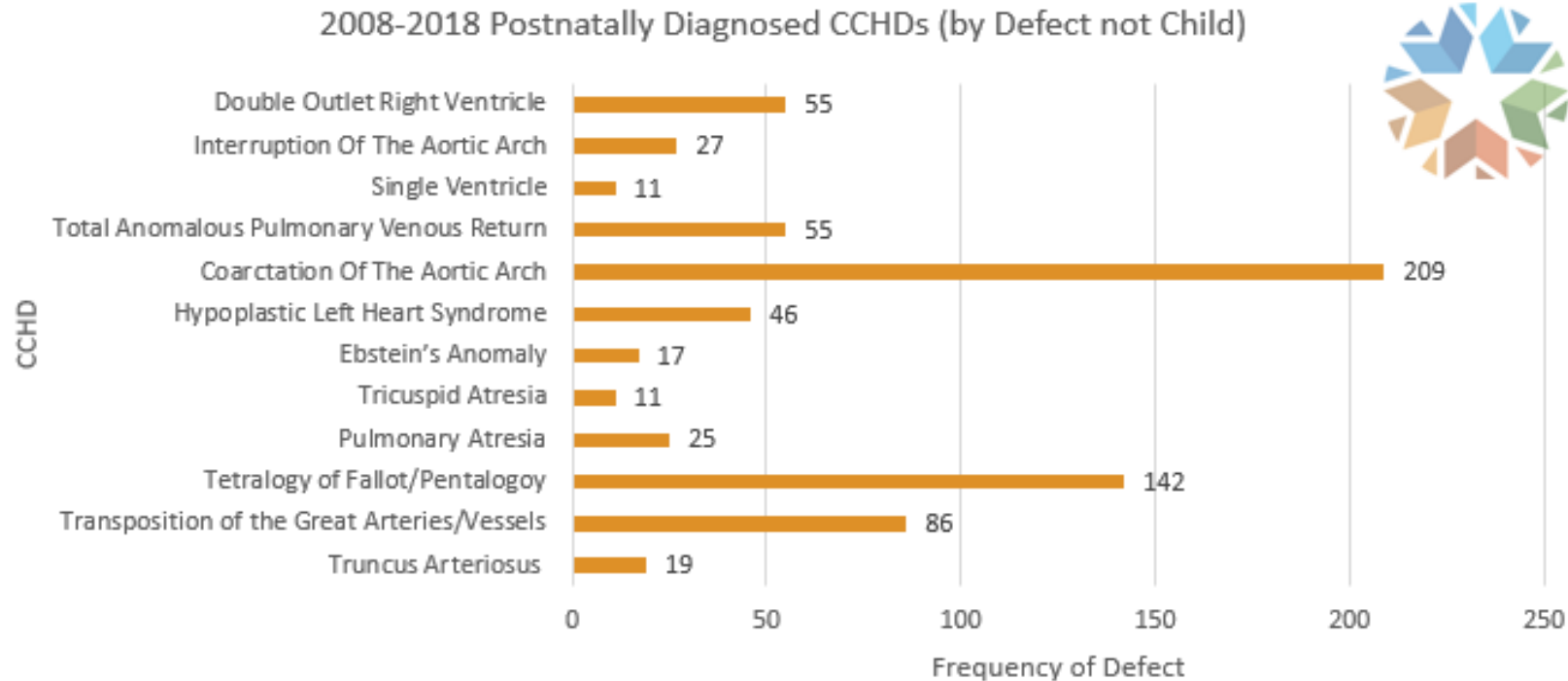
# CCHD: What to Watch For

## 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.**



# CCHDs in Oklahoma



Data provided by the Oklahoma Birth Defects Registry. Data does not reflect cases identified solely through pulse oximetry screening for CCHDs.



# Pulse-Oximetry

## The Screen and the Oximeter

# Pulse Oximetry: Context

## Who is screened?

- **All newborns:**
  - Must be calm and well; not crying
  - Warm extremities (temperature affects readings)
  - Skin clean and 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



# 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 and Guidelines

# How is the Screen Performed?

1. **Select site:** right hand; either foot.
2. **Place** photodetector on outer aspect of hand/foot (under 4<sup>th</sup>-5<sup>th</sup> 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

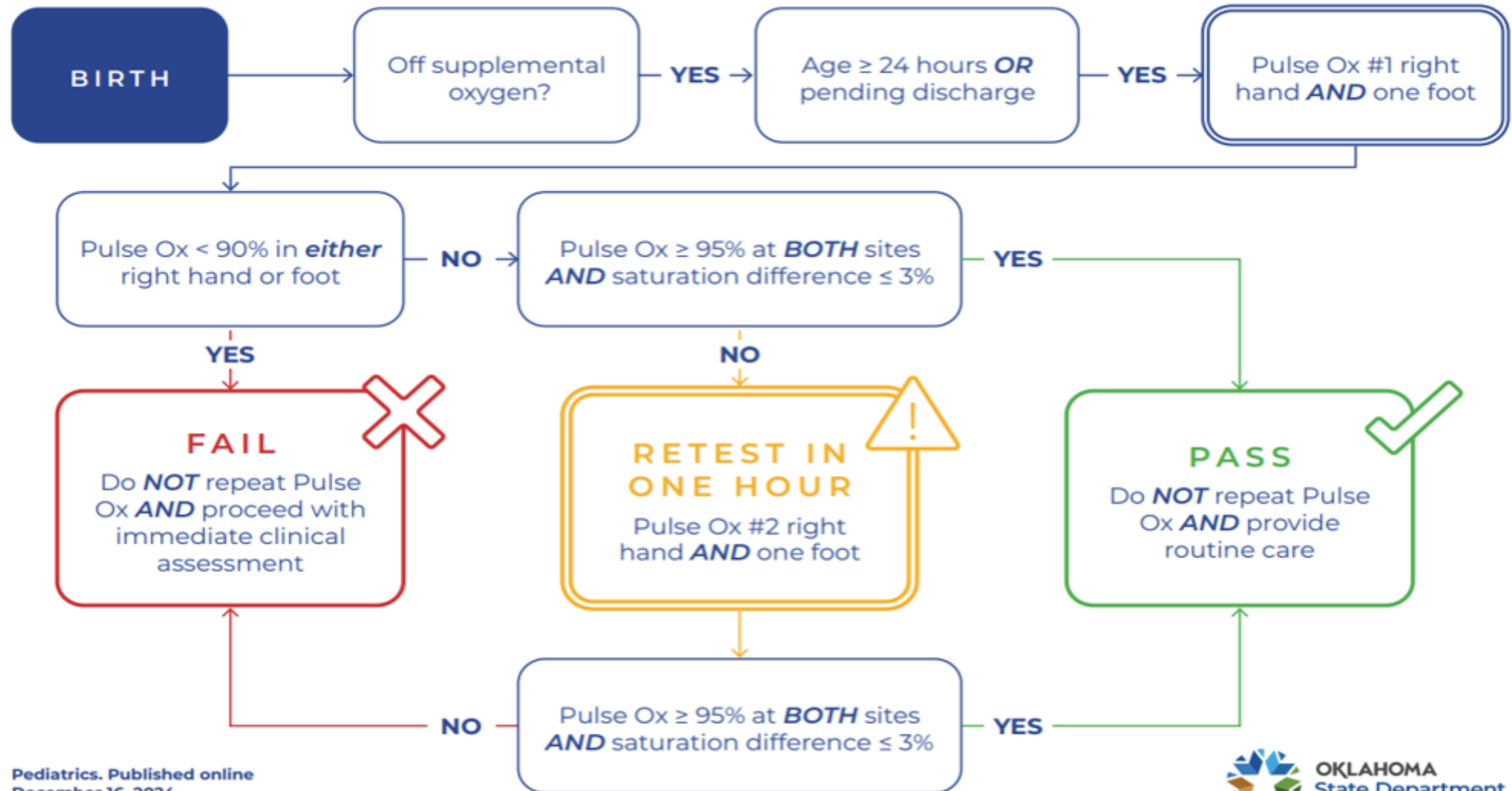
- If disposable, use a new, clean sensor; if reusable, clean between use
- Clean according to manufacturer recommendations
- Ensure newborn is calm and warm, not crying; encourage family involvement
- Ensure newborn skin is clean and dry
- Ensure no gaps between sensor and newborn's skin
- Light emitter 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 and 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 – Updated Algorithm, January 2025



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# 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



## Reporting Results for CCHD: Filter Paper

[illegible]

**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 and fax a copy to the NBS Program using fax number 405-900-7556.

- Pulse Oximetry Screen: Check Only ONE, do not leave blank
  - Pass
  - Fail
  - Not Performed
  - Refused
  - Echo

|                                   |                               |                                        |                                  |                               |
|-----------------------------------|-------------------------------|----------------------------------------|----------------------------------|-------------------------------|
| <b>PULSE OXIMETRY/CCHD SCREEN</b> |                               |                                        |                                  |                               |
| <input type="checkbox"/> Pass     | <input type="checkbox"/> Fail | <input type="checkbox"/> Not Performed | <input type="checkbox"/> Refused | <input type="checkbox"/> Echo |

# 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**



## For Reference...

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



**Thank you for  
your time!**

**Questions?**

