Newborn Bloodspot Screening

State of Maryland
Department of Health and Mental Hygiene
1770 Ashland Avenue
Baltimore, Maryland 21205

Maryland Newborn Screening Laboratory
Phone # 443-681-3900
Maryland Newborn Screening Follow-Up
Phone # 443-681-3916
Fax # 443-681-4500

What is Newborn Bloodspot Screening?

- Newborn Bloodspot Screening (NBS) is a service provided by the Maryland Department of Health and Mental Hygiene for families with new babies.
- NBS helps identify newborn babies with certain rare, serious disorders of body chemistry that if not detected early can cause mental retardation, serious illness or even death of the baby.
- NBS screens for over 50 possible disorders of body chemistry.

Screening vs. Diagnostic Testing

- Screening Tests (such as Newborn Screening):

  Distinguish those who probably have the disorder from those who probably do not have the disorder

- Diagnostic Tests (Laboratory tests):

  Establish the diagnosis of a particular disorder in a particular patient

Newborn Bloodspot Screening: It's not just a "PKU" anymore

- Calling the newborn bloodspot screening a "PKU" is misleading
- PKU is just 1 of over 50 disorders included in the newborn screen
- NBS screens for certain endocrine disorders; hemoglobin disorders; cystic fibrosis; and disorders breaking down lactose *(sugar in milk-based formulas and in breast milk)*, as well as breaking down fats and proteins
- Some of these disorders are life-threatening and need immediate intervention

What should parents know about NBS?

- NBS is designed to identify a possible disorder in their baby before any symptoms are present.

- Most of the disorders are rare. The most common disorders identified on NBS in Maryland are congenital hypothyroidism and sickle cell disease.
  - Symptoms of hypothyroidism are usually not evident in a baby until irreversible brain damage has occurred.
  - Early treatment with antibiotics can save the life of a baby with sickle cell disease.

- The most important teaching point…..*NBS can help prevent developmental delays and may save their baby's life!!*

Parents need to understand that this testing could save their baby's life!

Newborn bloodspot screening must be offered to all babies born in Maryland.

In 2008, the State of Maryland changed from an informed consent policy to an **informed dissent policy**..

Under the informed dissent policy, parents must be informed about the purpose of newborn bloodspot screening. It is the birth facility's responsibility to educate parents about the purpose for newborn bloodspot screening. ***Written consent is no longer required.*** Documentation is only needed ***if the parent refuses*** newborn screening.

If a Parent Refuses NBS For their Baby

- ***This refusal must be in written form with a parent's signature*** indicating they have been informed of the risks and benefits of newborn bloodspot screening and have chosen not to have their baby tested.

- The NBS Follow-Up Unit must also be notified **within 12 hours** of refusal. We will contact the family and discuss risks and benefits of newborn bloodspot screening. **Please call 443-681-3916 or fax refusal form to 443-681-4505.**

REFUSAL FORM - NEWBORN SCREENING

Baby's Name_____ **Date of Birth**_____

Hospital of Birth _____ **Medical Record Number**_____

I understand that:

The State of Maryland and the American Academy of Pediatrics strongly recommend newborn screening. Newborn screening is considered part of good baby care.

Newborn babies are tested for some conditions that cause mental retardation, other serious health problems and even death. Maryland tests babies for all the conditions recommended by the March of Dimes, the American Academy of Pediatrics and the American College of Medical Genetics. Although these disorders are rare, each month several babies are found to have a disorder identified by the newborn screen.

Treatment, if it is started early, can help to prevent the problems caused by these conditions. Every baby found to have a disorder will have access to the best treatment available.

Testing all babies is important because babies with these conditions usually look normal.

The tests are done on a small amount of the baby's blood. The blood is collected by pricking the baby's heel.

I understand that if my baby has one of these disorders, and does not have newborn screening, the delay in diagnosis and treatment can result in severe health problems, mental retardation or even death.

I have been provided with information about newborn screening. I know that if I have additional questions I can contact the Newborn Screening Laboratory at the State Health Department at 410-767-6099 or I can go to the State's website at http://dhmh.maryland.gov/labs/html/nbs.html.

I have discussed newborn screening with my baby's doctor or nurse.

_____M.D./R.N._____

Doctor's /Nurse's Name Phone Number

My questions have been answered to my satisfaction.

Nevertheless, I do not agree to the collection of a blood sample from my baby for the newborn screening tests.

I accept full responsibility for the decision not to permit my baby to have newborn screening performed.

I release and hold harmless the Maryland Department of Health and Mental Hygiene, the hospital of birth, and the person responsible for collecting the newborn screening sample, for any injury, illness, or medical condition to my child, or even the death of my child, any of which may be caused by a disorder that is screened for under the State's newborn screening comprehensive testing panel, which screening I am hereby refusing for my child.

Parent/Guardian's Name_____ **Signature** _____

Address_____ **Phone Number** _____

Date_____ **Witness**_____ **Signature**_____

DHMH#1263 Maryland Department of Health and Mental Hygiene Revised: 7/23/2010

When is Newborn Bloodspot Screening Performed?

- Timing of the NBS is crucial.
- For a well baby, the initial NBS should be collected when the baby is 24 to 72 hours old ***and*** has had at least 24 hours of feeding.
  - Results for CAH and T4 are invalid at less than ***24 hours of age***.
  - Results for Galactose and Amino Acids are valid only if baby is at least ***24 hours of age*** and has had at least ***24 hours of feeding***.
- ***It is very important to record birth time, 1st feeding time and collection time on the collection card.***

When is Newborn Bloodspot Screening Performed?

- It is the birth hospital's responsibility to make sure the initial NBS specimen is collected on well babies after 24 hours of age ***AND*** after 24 hours of feeding.

- If baby is discharged prior to 24 hours of age, or had less than 24 hours of feedings prior to the specimen collection, a repeat NBS needs to be collected as soon as possible.

- The State of Maryland has a two tier NBS system. All babies should have a second NBS collected after 7-10 days of age. This is usually done in the physician's office at the two week check-up.

When is Newborn Bloodspot Screening Performed for NICU Babies?

- There is a different schedule for babies who are in the special care nursery (SCN) or neonatal intensive care unit (NICU).
- The first NBS should be collected promptly after admission to the SCN or NICU. This specimen should be collected PRIOR to any blood transfusion.

  Results for Hemoglobin, Biotinidase and GALT are all affected by transfusion.

- A second NBS should be collected at 2-3 days of age.
- A third NBS should be collected at 10 days of age (or at discharge if baby is well enough to go home before 10 days of age).
- A fourth NBS should be collected at 1 month of age *or* discharge from the hospital, if prior to one month of age.

The Role of the Hospital

- Educate family and notify follow-up unit of any informed dissent
- Fill out the form completely and accurately
- Assure appropriate timing of the specimen
- Collect newborn screening specimen
- Send by courier to the lab within 24 hours
- Assist with follow up when called

What conditions are included in Newborn Bloodspot Screening?

Enzyme Disorders:

-Biotinidase deficiency

-Galactosemia

Biotinidase Deficiency

- Biotin is one of the B vitamins that helps break down proteins.
- Biotinidase removes biotin from the protein after the protein has been broken down so the body can reuse the biotin.
- In biotinidase deficiency, the biotin cannot be re-used so the supply in the body decreases.
- Individuals with biotinidase deficiency can not obtain enough biotin through their diet alone.
- Treatment involves taking biotin supplements. If not treated, individuals can have developmental delays and deafness and may have seizures, as well as developing hair and skin problems.
- This disorder is suggested by NBS if there is an abnormal Biotinidase level.

Galactosemia

•Galactosemia is a disorder in which a baby cannot metabolize galactose, which is broken down from lactose (the sugar in milk products).

Normal metabolic pathway:

Milk ⇒ Lactose ⇒ Galactose ⇒ Glucose ⇒ Energy

•A baby with classical galactosemia has an abnormal amount of the GALT enzyme and the galactose level is elevated. ***Classical galactosemia is a life threatening condition. Save lives through prompt screening!***

Metabolic pathway in Galactosemia:

Milk ⇒ Lactose ⇒ ↑Galactose ~~⇒~~ Glucose ⇒ Energy

•To help test for galactosemia, it is very important to note whether baby is breast feeding, feeding with a lactose formula (milk-based) or a non-lactose formula (soy-based) at the time of the collection of the NBS.

Galactosemia

•Galactose builds up in the body and can cause liver and kidney problems, as well as cataracts.

•Classical galactosemia is the complete lack of the GALT enzyme. This form of galactosemia is life threatening and can cause death in the first 5-10 days of life, usually from sepsis.

•The GALT enzyme can be normal and the baby may still have a form of galactosemia. Other enzymes are also used to break down galactose. If the baby has a normal GALT and elevated galactose on NBS, further testing is needed.

•Treatment for galactosemia involves use of a soy based formula like Isomil® or ProSobee®

•NBS gives a qualitative measure of GALT and also measures the amount of galactose in the blood.

What conditions are included in Newborn Bloodspot Screening?

Fatty Acid Oxidation Disorders:

- NBS currently tests for 13 different fatty acid oxidation disorders.
- Some babies are missing an important enzyme to break down fatty acids.
- Different enzymes are needed to break down long, medium and short chain fatty acids.
- Some babies cannot break down stored fats and some babies can not tolerate any fat.
- The name of the disorder is based on the missing enzyme.
- Affected infants require a constant source of energy and **CANNOT** go without eating. Fasting can cause brain damage and eventually death..
- These disorders are suggested in NBS by elevations in the Acylcarnitine Profile.

What conditions are included in Newborn Bloodspot Screening?

Amino Acid and Organic Acid Disorders:

- NBS currently screens for 18 different disorders in these two groups

- Some babies are missing an enzyme for breaking down certain amino acids or proteins

- Inability to break down proteins causes toxic levels of organic acids and/or amino acids to build up in the body

- The name of disorder is often based on the name of the amino acid or organic acid involved.

- These disorders are suggested in NBS by either elevations in the Amino Acid Profile or by certain elevations in the Acylcarnitine Profile.

What conditions are included in Newborn Bloodspot Screening?

Amino Acid and Organic Acid Disorders:

•Phenylketonuria (PKU) is an amino acid disorder. It is caused by the inability to completely break down the protein called *phenylalanine*. PKU needs to be treated promptly to prevent irreversible brain damage.

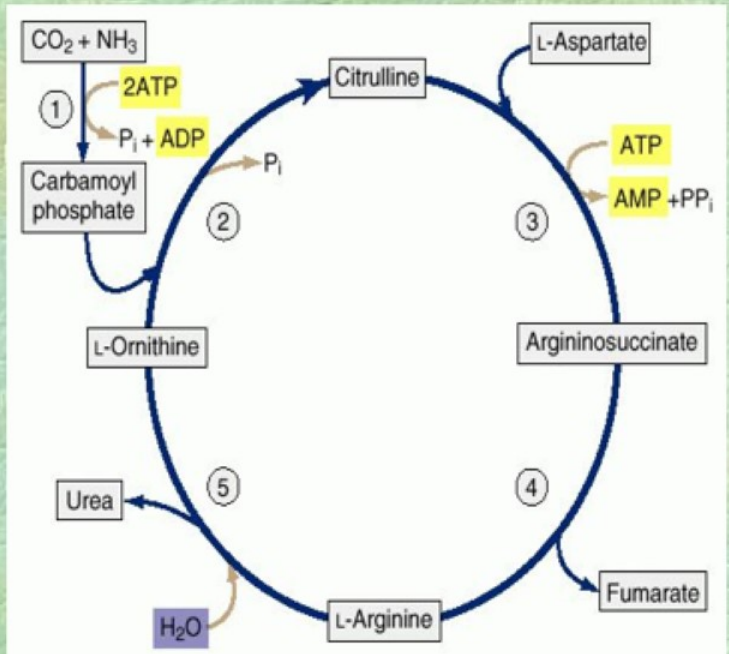
•Maple Syrup Urine Disease or MSUD is also an amino acid disorder. MSUD is caused by the inability to completely break down the branched chain amino acids – *leucine, isoleucine* and *valine*. ***It is very important to know MSUD is a life-threatening condition.*** The baby's urine or ear wax can have a sweet smell like maple syrup. If any baby is noted to smell like maple syrup, the baby needs to be evaluated immediately for possible MSUD, regardless of NBS results.

•All of the amino acid and organic acid disorders need to be treated promptly. Treatment involves providing the infant with a special diet and/or supplements.

What conditions are included in Newborn Bloodspot Screening?

Urea Cycle Disorders:

- NBS currently screens for 3 urea cycle disorders.
- Some babies are missing enzymes for breaking down certain amino acids used in the urea cycle.
- Inability to break down these proteins causes ammonia levels to increase.
- Babies may become lethargic and begin to seize prior to discharge from the hospital.
- All of these disorders need to be treated promptly. Treatment involves giving the baby a special diet and/or supplements.
- It is important to note that not all urea cycle disorders are picked up by NBS



KEY TO ENZYMES (Circled Numbers)

1. Carbamoyl-phosphate synthase (ammonia)
2. Ornithine carbamoyltransferase
3. Argininosuccinate synthase
4. Argininosuccinate lyase
5. Arginase

- These disorders are suggested in NBS secondary to the elevations of certain amino acids in the amino acid profile.

What conditions are included in Newborn Bloodspot Screening?

Endocrine Disorders

-Congenital Adrenal Hyperplasia

-Congenital Hypothyroidism

Congenital Adrenal Hyperplasia (CAH)

- Caused by defects in enzymes used for hormone production, including sex hormones and aldosterone.

- Females may present at birth with ambiguous genitalia causing gender misassignment. Males may appear physically normal at birth.

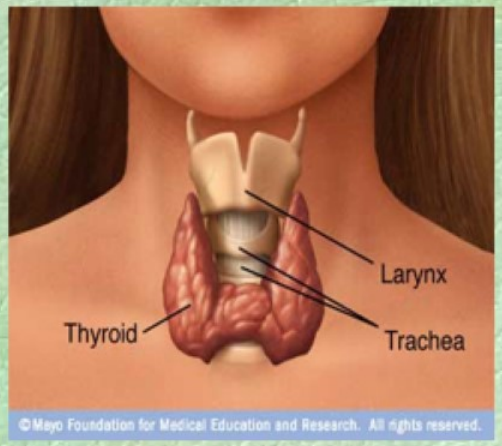
- Classical CAH is life threatening. Crisis symptoms can occur soon after birth. Within a few weeks the baby may present with dehydration, vomiting, lethargy, poor feeding and shock.

- A normal sodium level <u>does not</u> rule out all forms of CAH.

- Other forms of CAH may result in virilization of females and premature bone growth.

- This disorder is suggested in NBS by an elevated 17-OHP level. The 17-OHP level can be elevated in sick and premature infants as well.

Congenital Hypothyroidism



- One of the most common disorders identified through NBS
- Caused by the inability to secrete or produce thyroxine
- Baby may appear normal at birth, but could also have enlarged tongue or lump in the neck
- Most common cause of preventable brain damage
- Primary reason for 2nd NBS since baby may not have a low thyroxine level in the first 24-48 hours of life due to maternal thyroxine levels or medication
- Goal is to initiate treatment and have appropriate thyroxine levels by 6 weeks of age
- Requires lifetime treatment with hormone therapy
- This disorder is suggested through NBS by a low Thyroxine level and an elevated TSH level. However, there are also forms of hypothyroidism where the Thyroxine level is low and the TSH is normal.

What conditions are included in Newborn Bloodspot Screening?

Hemoglobin Disorders

- NBS screens for Sickle cell disease and other hemoglobinopathies

- Recessively inherited

- Some hemoglobin disorders are caused by a defect in the structure of hemoglobin in red blood cells

- In sickle cell disease the shape of the red blood cell transforms into a “sickle” shape and causes blood to back up in the body, causing pain and possible damage to body organs. There is also a greater risk for infection in babies and young children.

- Effective treatment helps reduce problems associated with sickle cell disease.

What conditions are included in Newborn Bloodspot Screening?

Cystic Fibrosis

- NBS screens for Cystic Fibrosis by measuring immunoreactive trypsinogen levels in the blood.

- Cystic Fibrosis causes thick, sticky mucus in the lungs which leads to problems with breathing and frequent lung infections.

- Babies may have problems digesting food, causing slow growth.

- Treatment includes breathing treatments (including chest percussion) as well as antibiotics for the lungs. Medicine and a special diet are given to babies with digestive problems.

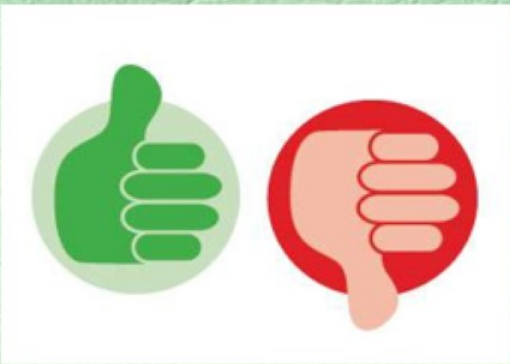
- Early identification and treatment provides a better quality of life and a longer life span.

- Possible cystic fibrosis is suggested in NBS by elevations in the IRT (immunoreactive trypsinogen).

Delays in Newborn Bloodspot Screening

- Newborn Screening is a life saving practice
- Timing is crucial in newborn bloodspot screening
- Delays for any reason can cause infants with certain disorders to die before parents realize something is wrong
- The sooner a disorder is identified, the earlier treatment can be started
- Infant outcome depends on newborn screening practices

Specimen Quality



- The Maryland State Newborn Screening Laboratory receives hundreds of specimens each *day* - both from birth hospitals and provider offices.

- Unsatisfactory specimens slow down the testing.

- The specimen may be unsatisfactory secondary to missing vital information on the lab slip or blood spots which are not acceptable for testing.

Frequently Missing Information

- Birth Date and Collection Date
  - Used to determine age of infant at the time of collection
  - Date of collection also determines age of blood at the time of analysis

- First Feeding Date and Time
  - Used to determine if infant has had at least 24 hours of feeding.

This information is very important for proper laboratory analysis of the results. The Galactose and Amino Acid Profile will be reported as IMF (insufficient milk feeding) if 1st feeding date and time are not given.*

Frequently Missing Information

- Mother's Information
  - Used for identification of the baby and to contact Mom if there is a abnormal result

  *****Verify address and phone number at time of collection*****

- Provider Information
  - This is ***NOT*** the on-call doctor that is seeing the baby in the hospital
  - It is important to note **the provider that will be following the baby after discharge** so we can contact them if there is an abnormality and so the provider can receive a copy of the results of the newborn screen. Ask the family which doctor or clinic is going to care for their baby after discharge.

Frequently Missing Information

- Special Information Needed for Proper Interpretation

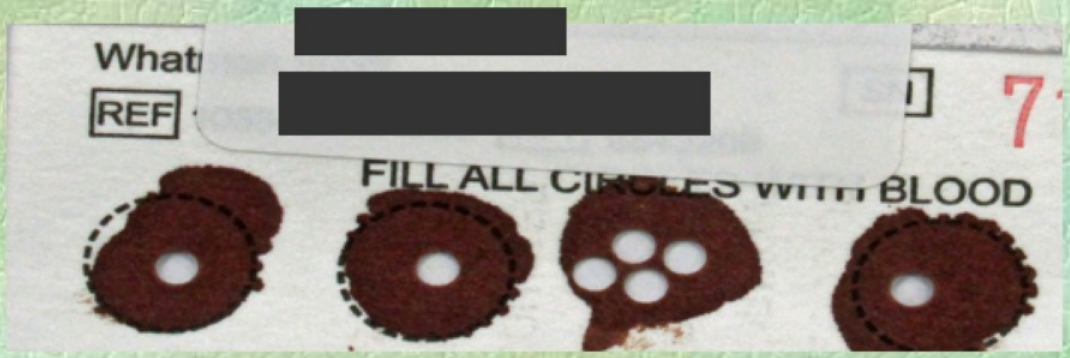
  - ✓ Weight – The test for cystic fibrosis is valid only if a baby is over 1500 grams. The cut-off values for congenital adrenal hyperplasia are also based on the infant's weight. Results will be reported as "Incomplete" if weight is missing.

  - ✓ Type of feeding – Please note all forms of nutrition given prior to the collection of the specimen. Note if baby is breast feeding only, taking lactose or lactose-free formula or breast feeding and taking formula.

    If baby is NPO, indicate whether or not baby is on TPN. The date and time TPN is started should be entered on the collection form in the space for 1st feeding date and time.

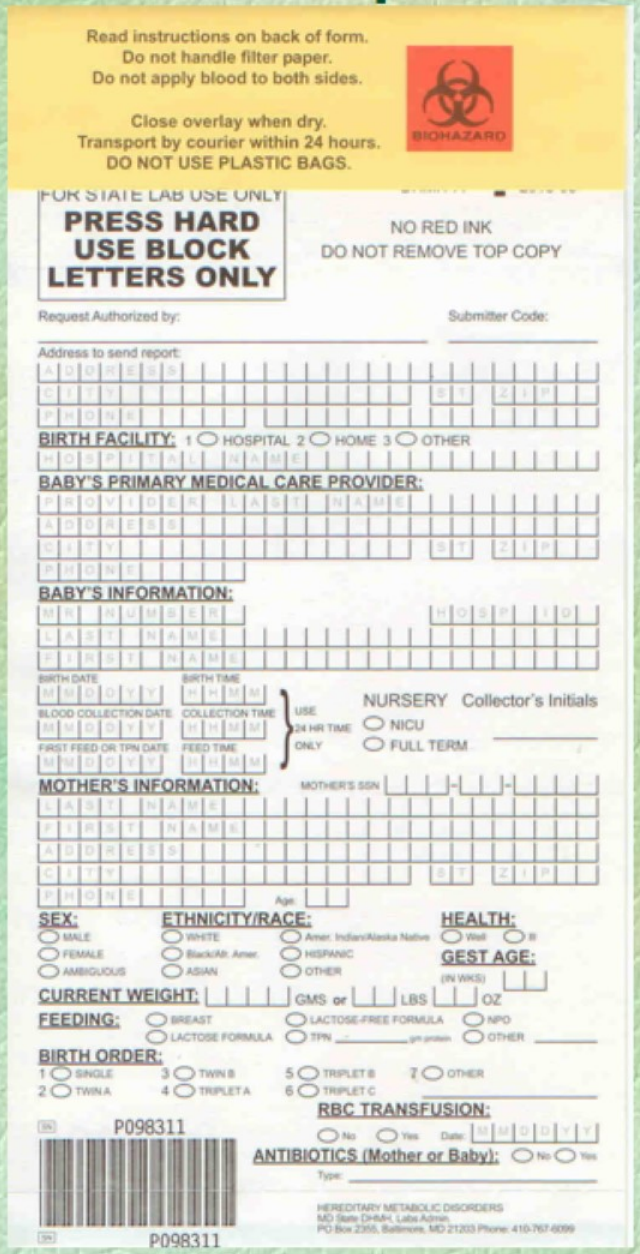
“Unsatisfactory Specimen”

- If the blood specimen does not give reliable results, it will have to be repeated
- Getting a repeat specimen can take weeks, putting the newborn baby at risk
- Always check the specimen before sending to make sure it appears acceptable



Collecting a Specimen

Completion of Collection Form


Read instructions on back of form.
Do not handle filter paper.
Do not apply blood to both sides.

Close overlay when dry.
Transport by courier within 24 hours.
DO NOT USE PLASTIC BAGS.

BIOHAZARD

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Request Authorized by:

Submitter Code:

Address to send report:

ADDRESS
CITY ST ZIP
PHONE

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER
HOSPITAL NAME

BABY'S PRIMARY MEDICAL CARE PROVIDER:
PROVIDER LAST NAME
ADDRESS
CITY ST ZIP
PHONE

BABY'S INFORMATION:
MR NUMBER HOSPID
LAST NAME
FIRST NAME

BIRTH DATE BIRTH TIME
BLOOD COLLECTION DATE COLLECTION TIME
FIRST FEED OR TPN DATE FEED TIME
USE 24 HR TIME ONLY

NURSERY Collector's Initials
NICU
FULL TERM

MOTHER'S INFORMATION:
MOTHER'S SSN
LAST NAME
FIRST NAME
ADDRESS
CITY ST ZIP
PHONE
Age

SEX:
MALE
FEMALE
AMBIGUOUS

ETHNICITY/RACE:
WHITE
Black/Afr. Amer.
ASIAN
Amer. Indian/Alaska Native
HISPANIC
OTHER

HEALTH:
Well
Ill

GEST AGE:
(IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING:
BREAST
LACTOSE FORMULA
LACTOSE-FREE FORMULA
TPN gm protein
NPO
OTHER

BIRTH ORDER:
1 SINGLE
2 TWIN A
3 TWIN B
4 TRIPLET A
5 TRIPLET B
6 TRIPLET C
7 OTHER

RBC TRANSFUSION:
No Yes Date:

ANTIBIOTICS (Mother or Baby): No Yes
Type:

P098311

HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin.
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

P098311

Use DHMH 77 (five spot card) for babies <7 days of age. More tests are run on the initial NBS so more blood is needed.

Check expiration date prior to collection of blood. If expired, call 410-767-6099 to request new collection cards.

Complete requested information on card prior to collection of blood

Please remember that **all requested information is important** for identification of the baby or for evaluation of the results.

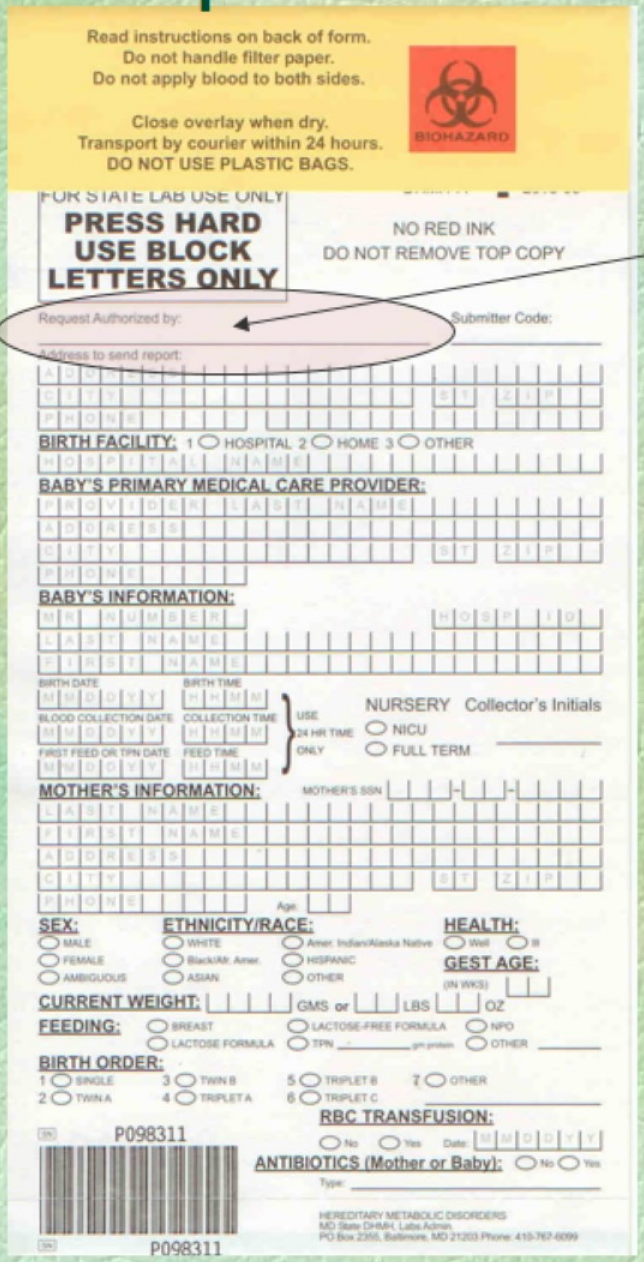
DHMH 79 (four spot card) is another collection card for babies >7 days of age. These are primarily used in the outpatient setting.

Completion of Collection Form

- Specimen cards are legal documents.
- Accurate information is crucial for valid and reliable testing, as well as linking of initial and repeat specimens.
- Use BLOCK LETTERS in the spaces provided. Use of BLOCK LETTERS allows for faster and more accurate data entry into the State Lab computer system.
- Stickers **should not** be applied to the front of the collection form. Identification stickers, if used, should be placed on the back side of the top white slip.

*****Do not place any stickers either on the front or the back of the actual filter paper. The front or back of the bloodspots should never be covered*****

Completion of DHMH 77 Collection Form


Read instructions on back of form.
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Request Authorized by:

Submitter Code:

Address to send report:

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER

BABY'S PRIMARY MEDICAL CARE PROVIDER:

BABY'S INFORMATION:

BIRTH DATE
BIRTH TIME
BLOOD COLLECTION DATE
COLLECTION TIME
FIRST FEED OR TPN DATE
FEED TIME
USE 24 HR TIME ONLY

NURSERY Collector's Initials
NICU
FULL TERM

MOTHER'S INFORMATION:

MOTHER'S SSN

Age:

SEX: MALE FEMALE AMBIGUOUS

ETHNICITY/RACE: WHITE Amer. Indian/Alaska Native Black/Afr. Amer. HISPANIC ASIAN OTHER

HEALTH: Well Ill

GEST AGE: (IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING: BREAST LACTOSE-FREE FORMULA NPO LACTOSE FORMULA TPN OTHER

BIRTH ORDER: 1 SINGLE 2 TWIN A 3 TWIN B 4 TRIPLET A 5 TRIPLET B 6 TRIPLET C 7 OTHER

RBC TRANSFUSION: No Yes Date:

ANTIBIOTICS (Mother or Baby): No Yes

Type:

P098311

P098311

HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin.
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

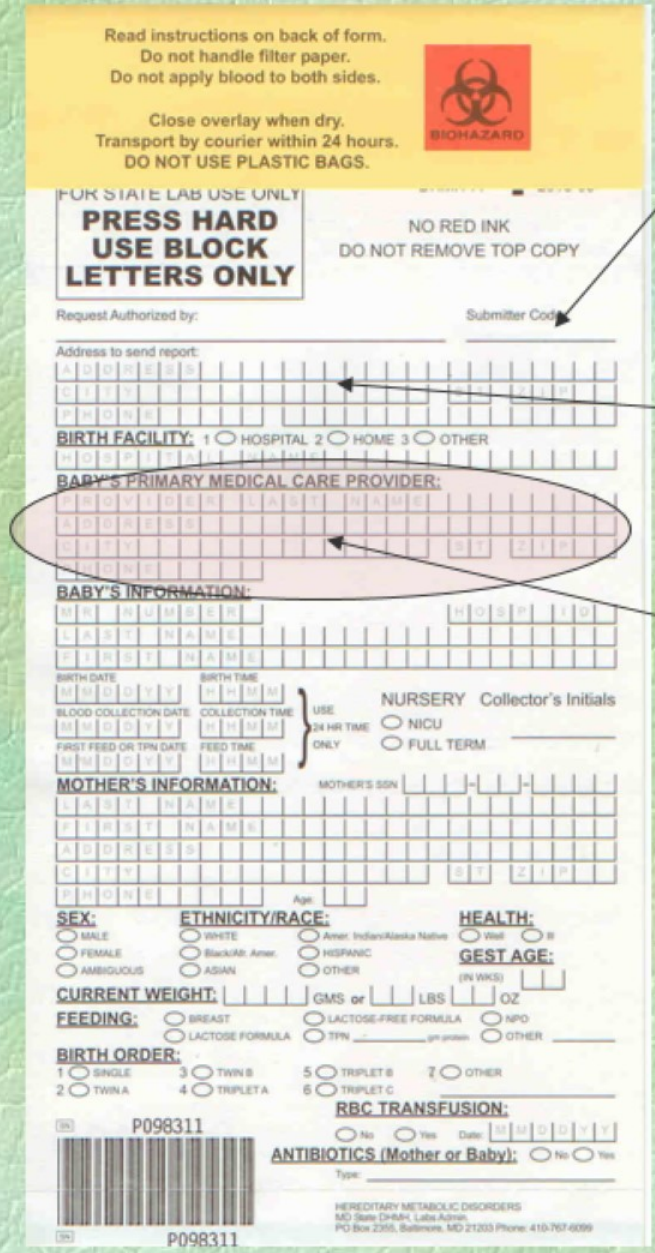
Note: Required changes to updated Newborn Screening form 77

Mandatory New Field –
all clinical tests must contain the name of the authorized person who ordered the test

An authorized person in the State of Maryland is:

- **A court of law**
- **A doctor of medicine or osteopathy**
- **A certified nurse midwife**
- **A certified nurse practitioner**
- **A physician's assistant**
- **Another person authorized to order laboratory tests under the Annotated Code of Maryland**

Completion of DHMH 77 Collection Form



Write in your ID CODE. If you do not know your code or do not have a code, please call 410-767-6099

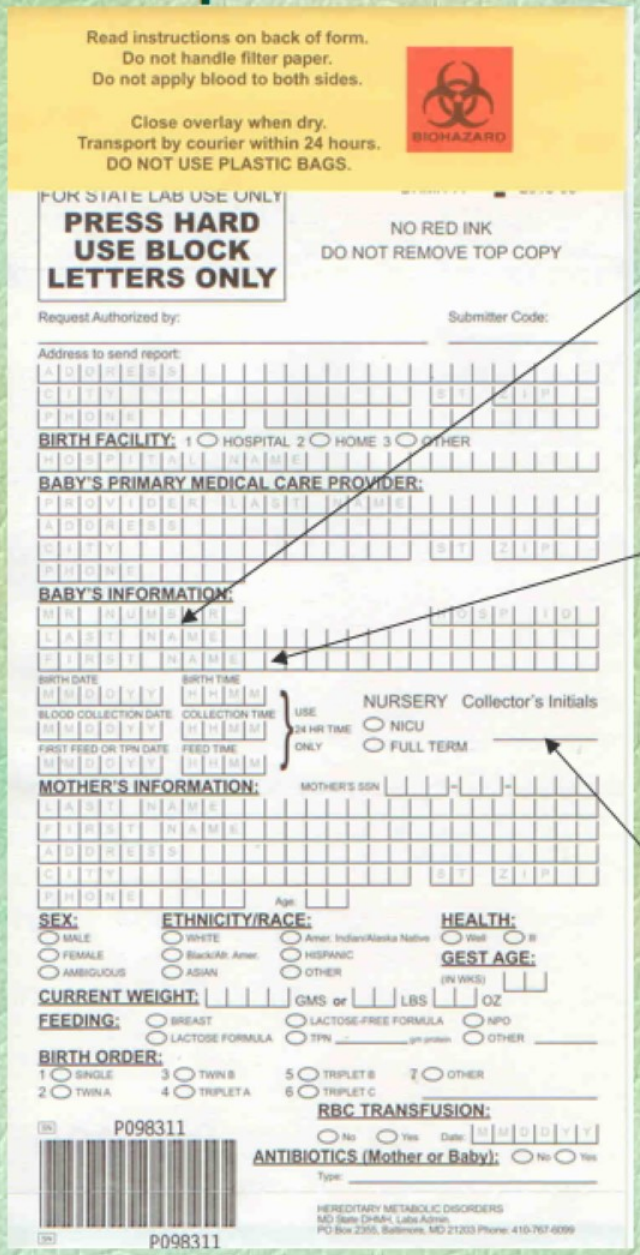
Using BLOCK LETTERS….

1. Record the name of the authorizing person
2. Record the address and phone number of the submitting hospital or birth center.

The baby's primary medical care provider should be **<u>the provider who will be caring for the baby after discharge</u>**. If the name is not in the chart, please ask the family. Adding this information will ensure the baby's doctor will get a copy of the results.

*****This Information is also very important if there is an abnormal result on the newborn screen so further testing can be initiated quickly.*****

Completion of DHMH 77 Collection Form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Request Authorized by:
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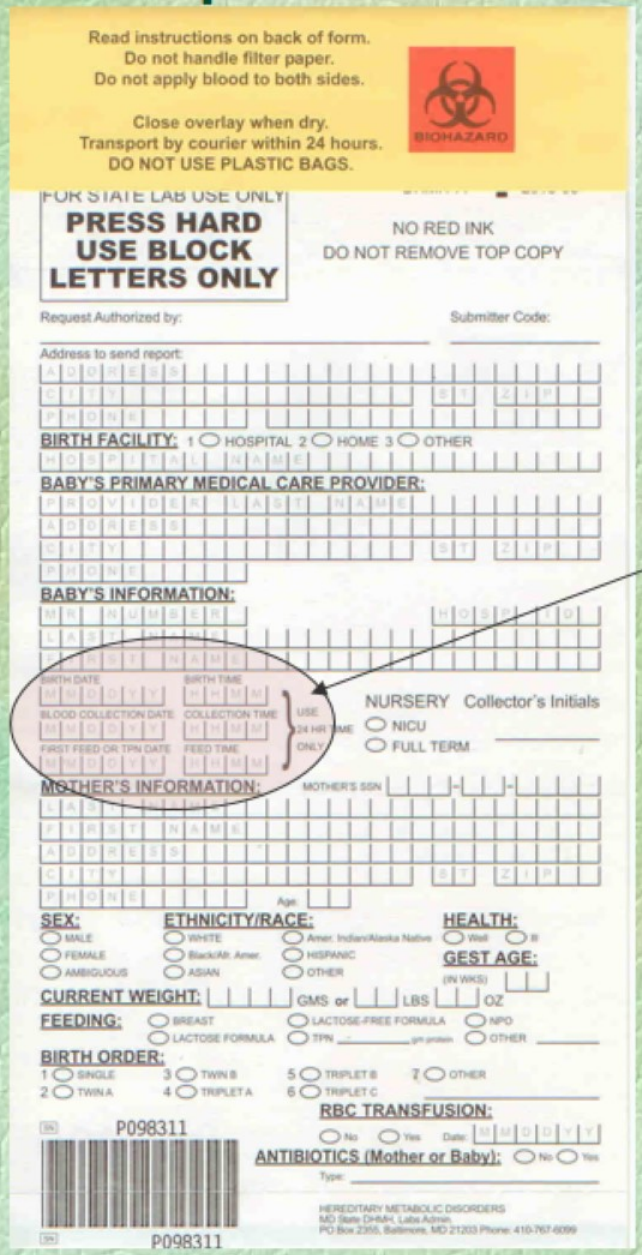
BABY'S PRIMARY MEDICAL CARE PROVIDER:
BABY'S INFORMATION:
BIRTH DATE
BIRTH TIME
BLOOD COLLECTION DATE
COLLECTION TIME
FIRST FEED OR TPN DATE
FEED TIME
USE 24 HR TIME ONLY
NURSERY
Collector's Initials
NICU
FULL TERM
MOTHER'S INFORMATION:
MOTHER'S SSN
Age
SEX:
MALE
FEMALE
AMBIGUOUS
ETHNICITY/RACE:
WHITE
Black/Afr. Amer.
ASIAN
Amer. Indian/Alaska Native
HISPANIC
OTHER
HEALTH:
Well
GEST AGE:
(IN WKS)
CURRENT WEIGHT:
GMS or
LBS
OZ
FEEDING:
BREAST
LACTOSE FORMULA
LACTOSE-FREE FORMULA
TPN
NPO
OTHER
BIRTH ORDER:
1 SINGLE
2 TWIN A
3 TWIN B
4 TRIPLET A
5 TRIPLET B
6 TRIPLET C
7 OTHER
RBC TRANSFUSION:
No
Yes
Date:
ANTIBIOTICS (Mother or Baby):
No
Yes
Type:
P098311
P098311
HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin.
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

Record the medical record number for the infant.

Record the baby's ***last name*** on the top line and ***first name*** on the bottom line in BLOCK LETTERS. (If known, this should be baby's permanent 1st and last name) ***Many private doctor's offices cannot identify a baby using the last name of the mother and the date of birth.***

Collector's Initials:
The person who collected the specimen for the baby should place his/her initials on this line.

Completion of DHMH 77 Collection Form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Submitter Code:

Address to send report:

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER

BABY'S PRIMARY MEDICAL CARE PROVIDER:

BABY'S INFORMATION:

BIRTH DATE
BIRTH TIME
BLOOD COLLECTION DATE
COLLECTION TIME
FIRST FEED OR TPN DATE
FEED TIME
USE 24 HR TIME ONLY

NURSERY Collector's Initials
NICU
FULL TERM

MOTHER'S INFORMATION:

MOTHER'S SSN

Age

SEX: MALE, FEMALE, AMBIGUOUS

ETHNICITY/RACE: WHITE, Black/Afr. Amer., ASIAN, Amer. Indian/Alaska Native, HISPANIC, OTHER

HEALTH: Well, Ill

GEST AGE: (IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING: BREAST, LACTOSE FORMULA, LACTOSE-FREE FORMULA, TPN, NPO, OTHER

BIRTH ORDER: 1 SINGLE, 2 TWIN A, 3 TWIN B, 4 TRIPLET A, 5 TRIPLET B, 6 TRIPLET C, 7 OTHER

RBC TRANSFUSION: No, Yes, Date:

ANTIBIOTICS (Mother or Baby): No, Yes

Type:

P098311

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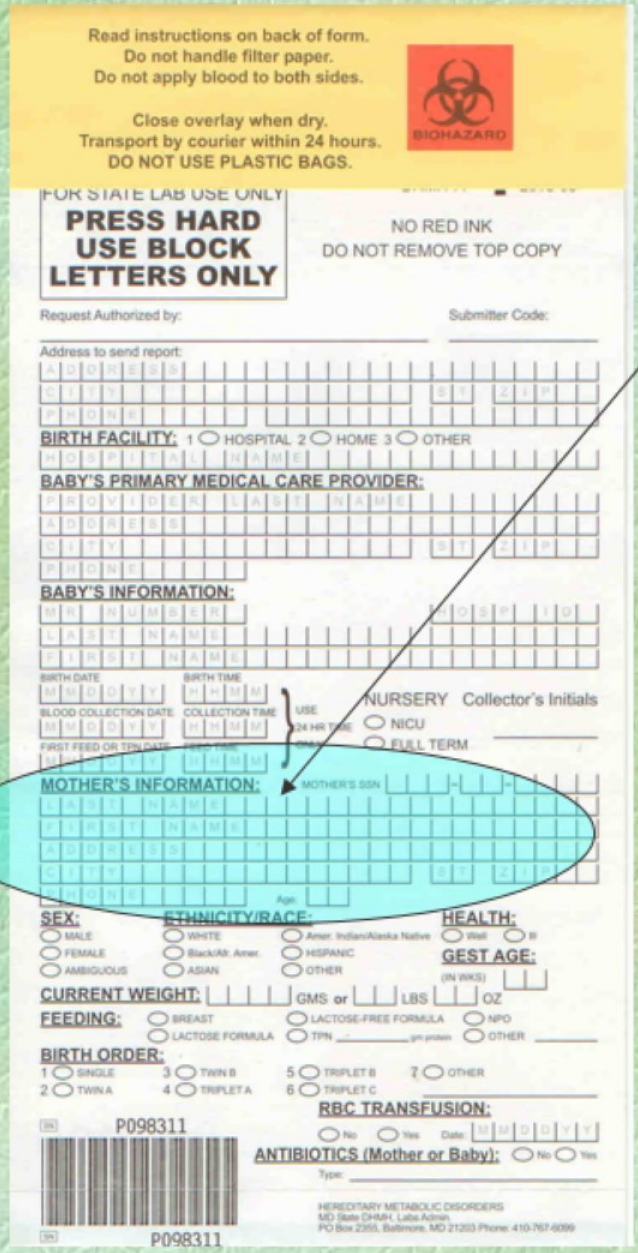
P098311

This information is very important.*

Complete all three of the dates and times
Use MM/DD/YY format and military time.

This information is used to determine age at time of collection and if baby has had enough protein prior to the test collection. Some of the test results are evaluated based on the infant's age at the time of collection.

Completion of DHMH 77 Collection Form


Read instructions on back of form.
Do not handle filter paper.
Do not apply blood to both sides.

Close overlay when dry.
Transport by courier within 24 hours.
DO NOT USE PLASTIC BAGS.

BIOHAZARD

FOR STATE LAB USE ONLY

PRESS HARD
USE BLOCK
LETTERS ONLY

NO RED INK
DO NOT REMOVE TOP COPY

Request Authorized by:

Submitter Code:

Address to send report:

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER

BABY'S PRIMARY MEDICAL CARE PROVIDER:

BABY'S INFORMATION:

BIRTH DATE

BIRTH TIME

BLOOD COLLECTION DATE

COLLECTION TIME

USE 24 HR TIME

NURSERY Collector's Initials

NICU

FULL TERM

MOTHER'S INFORMATION:

MOTHER'S SSN

Age:

SEX:
MALE
FEMALE
AMBIGUOUS

ETHNICITY/RACE:
WHITE
Amer. Indian/Alaska Native
Black/Afr. Amer.
HISPANIC
ASIAN
OTHER

HEALTH:
Well

GEST AGE:
(IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING:
BREAST
LACTOSE-FREE FORMULA
NPO
LACTOSE FORMULA
TPN
OTHER

BIRTH ORDER:
1 SINGLE
2 TWIN A
3 TWIN B
4 TRIPLET A
5 TRIPLET B
6 TRIPLET C
7 OTHER

RBC TRANSFUSION:
No Yes Date:

ANTIBIOTICS (Mother or Baby): No Yes
Type:

P098311

HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

P098311

Mother's Information:
It is important that this information is accurate so the baby can be located if there is a positive newborn screen.

******Verify address and phone number with the mother at the time of specimen collection.******

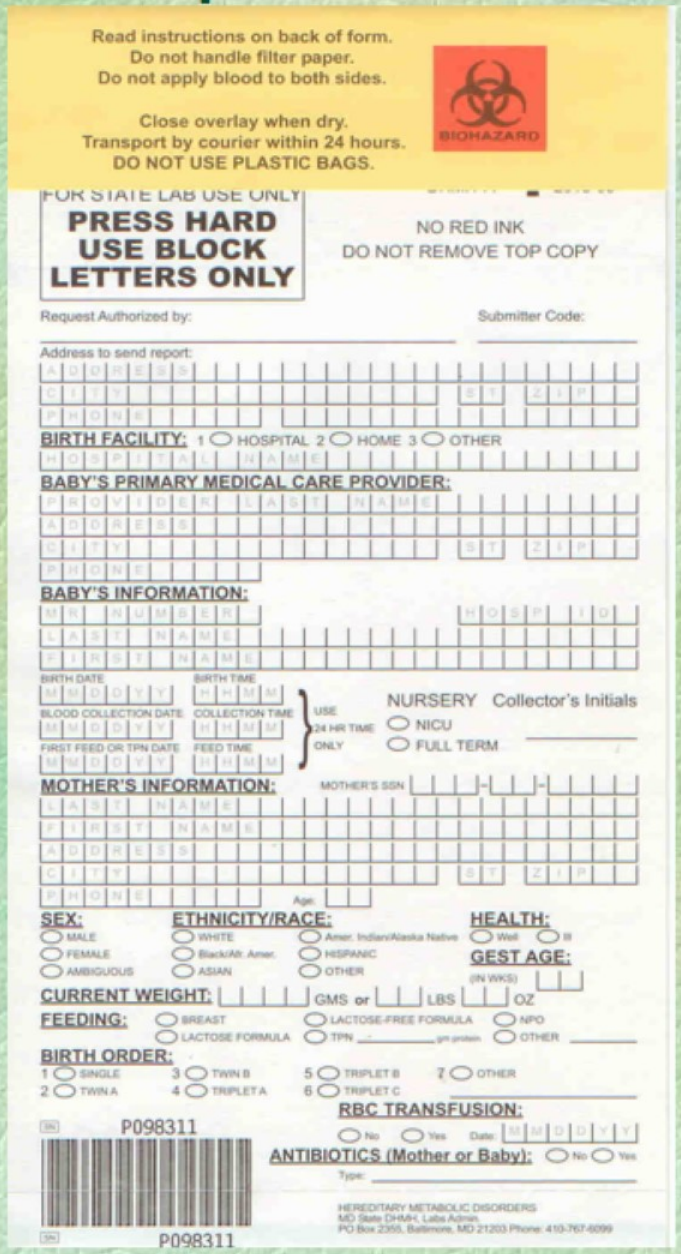
Abnormal results can be received on the weekend and information on the chart may not be readily available to a physician who is covering for the weekend.

The mother's social security number is used to help link the initial and subsequent specimens.

Using BLOCK LETTERS

1. Record mother's last name at time of the birth
2. Record mother's first name
3. Record mother's address
4. Record mother's city, state and zip code
5. Record phone number to contact mother.

Completion of DHMH 77 Collection Form



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Request Authorized by: Submitter Code:

Address to send report:
ADDRESS
CITY ST ZIP
PHONE

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER
HOSPITAL NAME

BABY'S PRIMARY MEDICAL CARE PROVIDER:
PROVIDER LAST NAME
ADDRESS
CITY ST ZIP
PHONE

BABY'S INFORMATION:
MR NUMBER HOSPID
LAST NAME
FIRST NAME

BIRTH DATE BIRTH TIME
BLOOD COLLECTION DATE COLLECTION TIME
FIRST FEED OR TPN DATE FEED TIME
USE 24 HR TIME ONLY

NURSERY Collector's Initials
NICU
FULL TERM

MOTHER'S INFORMATION: MOTHER'S SSN
LAST NAME
FIRST NAME
ADDRESS
CITY ST ZIP
PHONE Age:

SEX: MALE FEMALE AMBIGUOUS

ETHNICITY/RACE: WHITE Black/Afr. Amer. ASIAN Amer. Indian/Alaska Native HISPANIC OTHER

HEALTH: Well Ill

GEST AGE: (IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING: BREAST LACTOSE FORMULA LACTOSE-FREE FORMULA TPN NPO OTHER

BIRTH ORDER: 1 SINGLE 2 TWIN A 3 TWIN B 4 TRIPLET A 5 TRIPLET B 6 TRIPLET C 7 OTHER

RBC TRANSFUSION: No Yes Date:

ANTIBIOTICS (Mother or Baby): No Yes
Type:

P098311

HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin.
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

P098311

Mother's Information:
It is important that this information is accurate so the baby can be located if there is a positive newborn screen.

******Verify address and phone number with the mother at the time of specimen collection.******

Abnormal results can be received on the weekend and information on the chart may not be readily available to a physician who is covering for the weekend.

The mother's social security number is used to help link the initial and subsequent specimens.

Using BLOCK LETTERS

1. Record mother's last name at time of the birth
2. Record mother's first name
3. Record mother's address
4. Record mother's city, state and zip code
5. Record phone number to contact mother.

Completion of Collection Form

Occasionally, special circumstances arise such as in the case of an adoption, surrogacy or involvement of protective services.

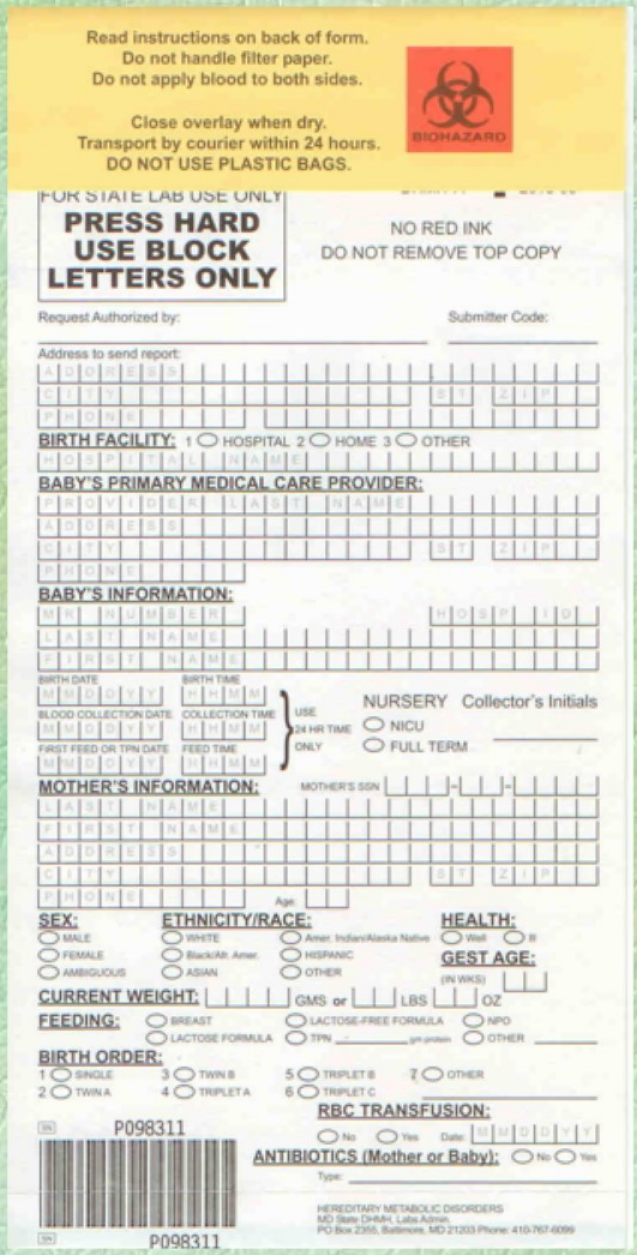
✓ *If the baby is being adopted, please write **"adoption"** on the lab slip and write in the adoptive parent's name and phone number. Also indicate birth mother's name on the lab slip.*

✓ *If the birth mother is a surrogate mother, please write **"surrogate"** on the lab slip and write in the contact information for the custodial parents. Also indicate birth mother's name on the lab slip.*

✓ *If the baby is discharged to protective services, please write **"protective services"** on the lab slip and indicate the name and phone number of the baby's case worker, along with the birth mother's name.*

*****The purpose of this information is to provide a way to find the infant with a positive result promptly in order to facilitate further testing.*****

Completion of DHMH 77 Collection Form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Request Authorized by:

Submitter Code:

Address to send report:

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER

BABY'S PRIMARY MEDICAL CARE PROVIDER:

BABY'S INFORMATION:

BIRTH DATE

BIRTH TIME

BLOOD COLLECTION DATE

COLLECTION TIME

FIRST FEED OR TPN DATE

FEED TIME

USE 24 HR TIME ONLY

NURSERY Collector's Initials

NICU

FULL TERM

MOTHER'S INFORMATION:

MOTHER'S SSN

Age

SEX:
MALE
FEMALE
AMBIGUOUS

ETHNICITY/RACE:
WHITE
Amer. Indian/Alaska Native
Black/Afr. Amer.
HISPANIC
ASIAN
OTHER

HEALTH:
Well
Ill

GEST AGE:
(IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING:
BREAST
LACTOSE-FREE FORMULA
NPO
LACTOSE FORMULA
TPN
OTHER

BIRTH ORDER:
1 SINGLE
2 TWIN A
3 TWIN B
4 TRIPLET A
5 TRIPLET B
6 TRIPLET C
7 OTHER

RBC TRANSFUSION:
No
Yes
Date:

ANTIBIOTICS (Mother or Baby):
No
Yes
Type:

P098311

HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin.
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

P098311

Sex:
Mark whether or not the baby is male or female. If sex cannot be determined secondary to ambiguous genitalia, mark the sex as ambiguous. This is very important information if the baby has an elevation in the CAH test.

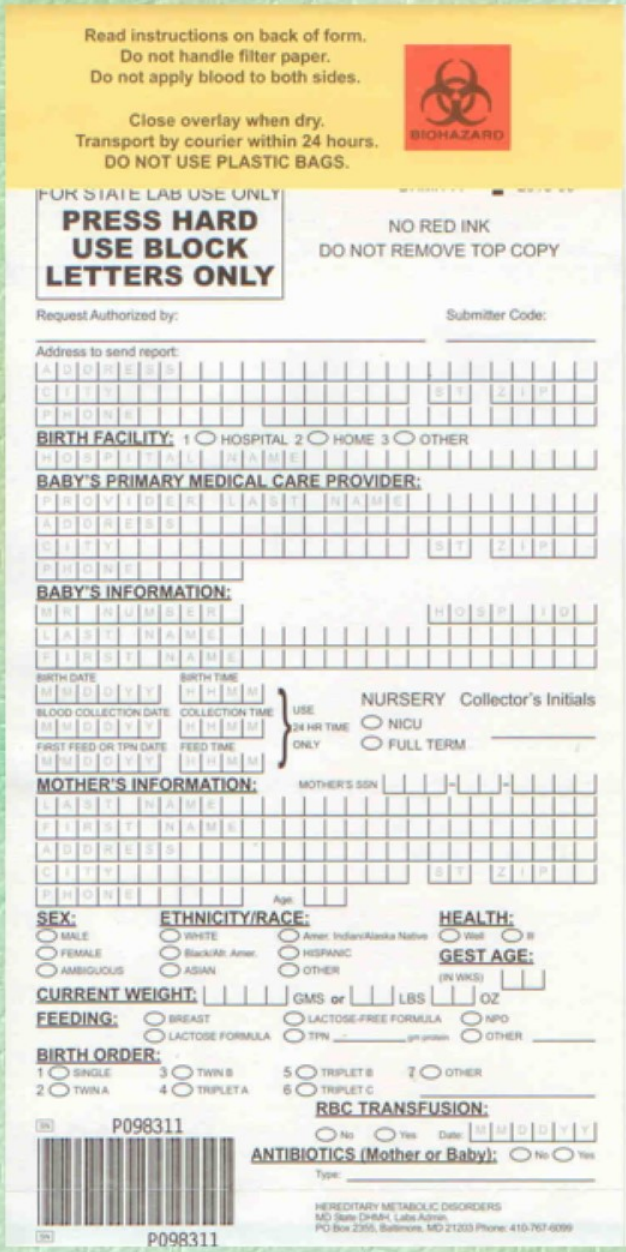
Ethnicity/Race:
Indicate ethnicity/race by marking in the oval space provided. This information is important to determine incidence of newborn screening abnormals by race and ethnicity. Some disorders are more common in specific ethnic groups.

Health:
Note whether baby is well or ill.

Gestational Age:
Record the newborn's gestational age at the time of birth. A baby's gestational age does not change after birth. It is important that this information is accurate as gestational age does correlate with some analyte levels and can be used to better interpret results.

Weight:
It is important to accurately enter the infant's birth weight as some tests have cut-offs based on the infant's weight at the time of specimen collection.

Completion of DHMH 77 Collection Form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BABY'S PRIMARY MEDICAL CARE PROVIDER:

BABY'S INFORMATION:

BIRTH DATE

BIRTH TIME

BLOOD COLLECTION DATE

COLLECTION TIME

FIRST FEED OR TPN DATE

FEED TIME

USE 24 HR TIME ONLY

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Age:

SEX: MALE, FEMALE, AMBIGUOUS

ETHNICITY/RACE: WHITE, Black/Afr. Amer., ASIAN, Amer. Indian/Alaska Native, HISPANIC, OTHER

HEALTH: Well, Ill

GEST AGE: (IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING: BREAST, LACTOSE FORMULA, LACTOSE-FREE FORMULA, TPN, NPO, OTHER

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RBC TRANSFUSION: No, Yes, Date:

ANTIBIOTICS (Mother or Baby): No, Yes

Type:

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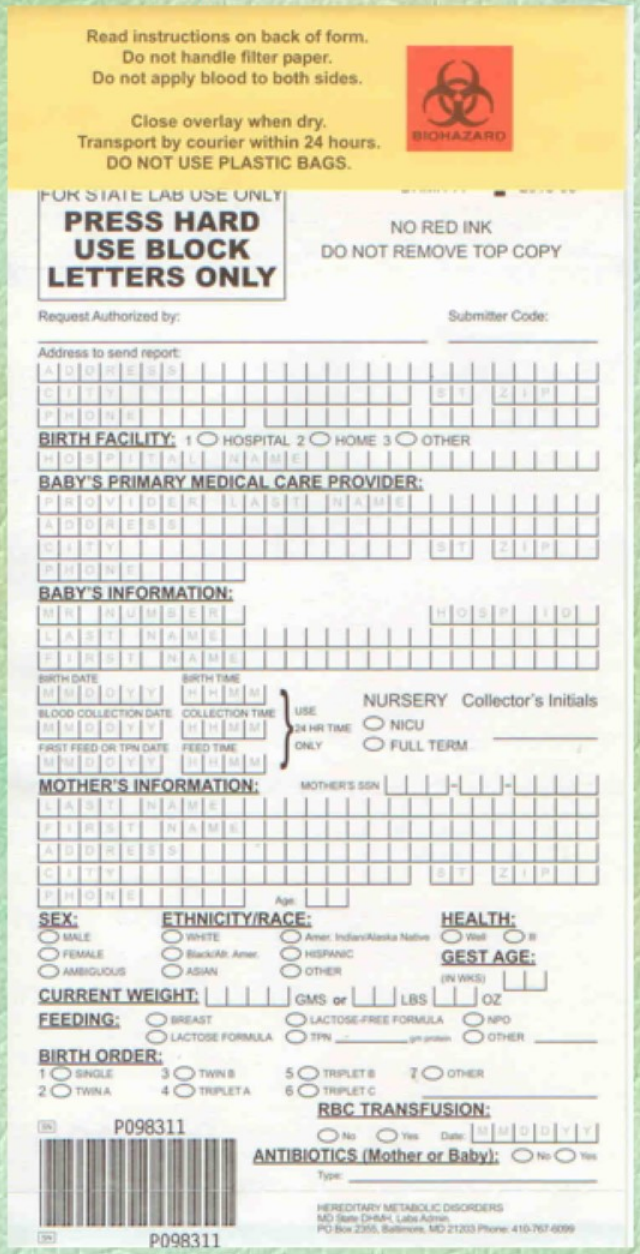
Feeding:
Indicate the type of feeding an infant is receiving. Soy formulas are lactose-free. Most regular formulas are lactose formulas. If baby is nursing and being supplemented with formula, please indicate both breast and type of formula.

*****It is very important to indicate feeding type because Galactosemia is a life-threatening inability to break down lactose*****

If a baby is NPO, but is also getting TPN, please indicate this along with the date and time TPN was started. This is important so the lab knows the baby has been receiving proteins for at least 24 hours.

Birth Order:
Indicate whether this is a single birth, twins, triplets, etc. If this was a multiple birth, it is very important to note which infant is Twin A, Twin B, Triplet A, etc. to help identify which subsequent specimen should be matched to the initial specimen.

Completion of DHMH 77 Collection Form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Request Authorized by:

Submitter Code:

Address to send report:

ADDRESS
CITY ST ZIP
PHONE

BIRTH FACILITY: 1 HOSPITAL 2 HOME 3 OTHER
HOSPITAL NAME

BABY'S PRIMARY MEDICAL CARE PROVIDER:
PROVIDER NAME
ADDRESS
CITY ST ZIP
PHONE

BABY'S INFORMATION:
MRN NUMBER HOSPID
LAST NAME
FIRST NAME

BIRTH DATE BIRTH TIME
BLOOD COLLECTION DATE COLLECTION TIME
FIRST FEED OR TPN DATE FEED TIME
USE 24 HR TIME ONLY

NURSERY Collector's Initials
NICU
FULL TERM

MOTHER'S INFORMATION:
MOTHER'S SSN
LAST NAME
FIRST NAME
ADDRESS
CITY ST ZIP
PHONE
Age

SEX:
MALE
FEMALE
AMBIGUOUS

ETHNICITY/RACE:
WHITE
Black/Afr. Amer.
ASIAN
Amer. Indian/Alaska Native
HISPANIC
OTHER

HEALTH:
Well
Ill

GEST AGE:
(IN WKS)

CURRENT WEIGHT: GMS or LBS OZ

FEEDING:
BREAST
LACTOSE FORMULA
LACTOSE-FREE FORMULA
TPN gm protein
NPO
OTHER

BIRTH ORDER:
1 SINGLE
2 TWIN A
3 TWIN B
4 TRIPLET A
5 TRIPLET B
6 TRIPLET C
7 OTHER

RBC TRANSFUSION:
No Yes Date:

ANTIBIOTICS (Mother or Baby): No Yes
Type:

P098311

HEREDITARY METABOLIC DISORDERS
MD State DHMH, Labs Admin.
PO Box 2355, Baltimore, MD 21203 Phone: 410-767-6099

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RBC Transfusion

Please indicate if baby has been transfused.
If transfused, indicate date of most recent transfusion.

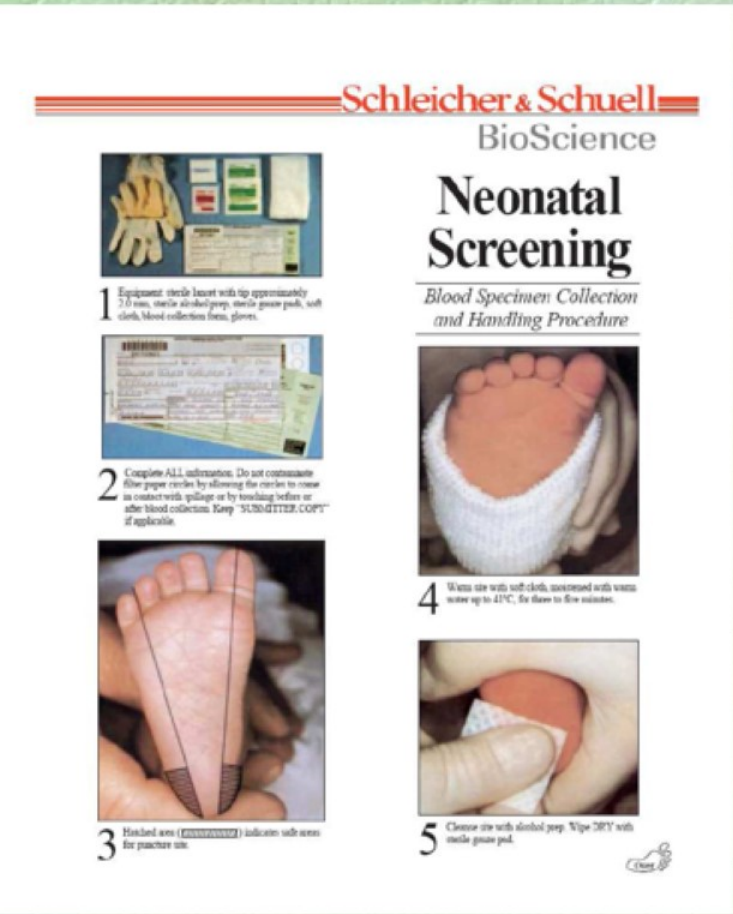
The first specimen needs to be collected prior to transfusion in order to obtain reliable results for Hemoglobin, Biotinidase and GALT.

Antibiotics

Please indicate if the baby is on antibiotics.
If so, indicate which antibiotics.
Certain antibiotics can cause elevations in the analytes identified through newborn screening.

New information requested –
Please indicate if mother or baby has been on antibiotics in last 48 hours

Collecting a Specimen



Once the collection form is completely and accurately filled out, gather supplies for the collection of the specimen

- ✓Sterile Lancet with a tip less than 2.0 mm (Scalpel bladed lancets are best)
- ✓Sterile alcohol swab
- ✓Sterile gauze pads
- ✓Soft cloth or heel warmer
- ✓Completed Blood Collection form
- ✓Gloves (powder free)

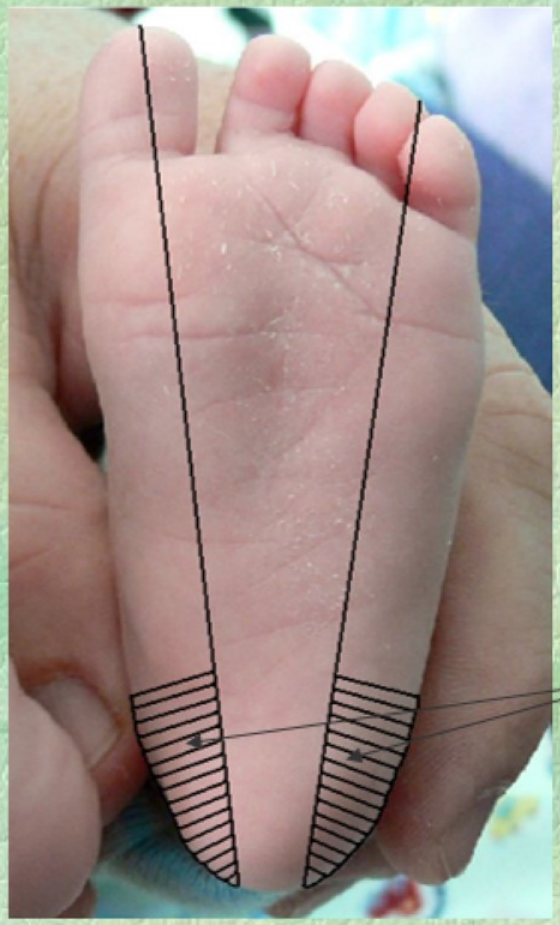
Preparation for neonatal capillary blood sampling

Warm infant's heel with soft cloth or diaper, moistened with warm water, for 3 to 5 minutes.

You can also use a commercially prepared disposable heat pack. (make sure to follow your facility's guidelines for using heat packs)

Place infant's heel in a dependent position, head higher than feet.

Recommended sites for neonatal capillary blood sampling



Puncture site should be on the medial or lateral portion of the plantar surface of the heel. (The plantar surface is the part of the foot that touches the floor if standing or walking.)

The ***shaded areas*** show the best sites for puncture. Use of these areas will help prevent possible damage to the heel bone and the nerves and arteries in the foot.

Neonatal capillary blood sampling

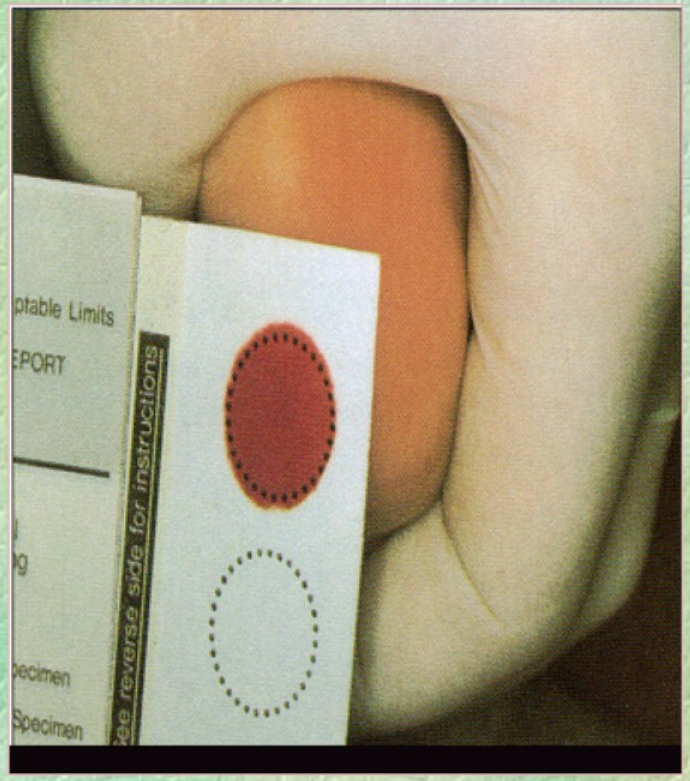
Cleanse site with alcohol prep and allow to dry.

Puncture heel with sterile lancet which has a puncture depth of less than 2.0 mm. The lancet should be labeled for use in newborn capillary specimen collection.

Wipe away first blood drop with sterile gauze pad.

Allow another LARGE blood drop to form.

Neonatal capillary blood sampling



Direct application of blood onto the filter paper is recommended. Capillector tubes should not be used as they may scratch the top of the filter paper.

Lightly touch filter paper to LARGE blood drop. Filter paper acts like a capillary tube, drawing blood into itself.

Allow blood to soak through and completely fill circle with SINGLE application. The blood should soak through the paper and be visible on the other side of the paper. *(To enhance blood flow, VERY GENTLE intermittent pressure may be applied to the heel. Do not milk or squeeze tissue next to the puncture site because this may cause serum to separate.)*

Apply blood to only one side of the filter paper. Fill remaining circles by lightly touching one LARGE blood drop to each circle.

If blood flow diminishes, clean a new site and repeat the process with a new sterile lancet.

Important Points to Remember

✓Do not touch the actual filter paper portion of the lab slip either before, during or after blood collection. Contamination of the filter paper with water, formula or powder from gloves will affect the results.

✓Check the specimen to make sure the blood saturated through the card and there is no overlapping of blood in the circles. If there is a problem with the specimen, the test should be repeated.

✓Allow specimen to dry on a clean flat non-absorbent surface for a minimum of 4 hours.

✓Completed specimen should be sent by courier to the Maryland State Laboratory within 24 hours of collection. Do not hold or "batch" specimens while waiting for several specimens to be sent together.

✓If the initial newborn screening specimen is unsatisfactory, needless delay will occur while the doctor and family are contacted to have another specimen collected.

Schleicher & Schuell

Simple Spot Check

Valid Specimen

Allow a sufficient quantity of blood to soak through to completely fill the pre-printed circle on the filter paper. Fill all required circles with blood. Do not layer successive drops of blood or apply blood more than once in the same collection circle. Avoid touching or smearing spots.

Invalid Specimens:

Specimen quantity insufficient for testing

Specimen appears scratched or abraded.

Specimen not dry before mailing.

Specimen appears supersaturated.

6. Specimen appears diluted, discolored or contaminated.

Specimen exhibits serum rings.

Specimen appears clotted or layered.

No blood.

Possible Causes:

- Removing filter paper before blood has completely filled circle or before blood has soaked through to second side.
- Applying blood to filter paper with a capillary tube.
- Touching filter paper before or after blood specimen collection with gloved or ungloved hands, hand lotion, etc.
- Allowing filter paper to come in contact with gloved or ungloved hands or substances such as hand lotion or powder, either before or after blood specimen collection.
- Applying blood with a capillary tube or other device.
- Mailing specimen before drying for a minimum of four hours.
- Applying excess blood to filter paper, usually with a device.
- Applying blood to both sides of filter paper.
- Squeezing or "milking" of area surrounding the puncture site.
- Allowing filter paper to come in contact with gloved or ungloved hands or substances such as alcohol, formula, antiseptic solutions, water, hand lotion or powder, etc., either before or after blood specimen collection.
- Exposing blood spots to direct heat.
- Not wiping alcohol from puncture site before making skin puncture.
- Allowing filter paper to come in contact with alcohol, hand lotion, etc.
- Squeezing area surrounding puncture site excessively.
- Drying specimen improperly.
- Applying blood to filter paper with a capillary tube.
- Touching the same circle on filter paper to blood drop several times.
- Filling circle on both sides of filter paper.
- Failure to obtain blood specimen.

Information provided by The New York State Department of Health.

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Schleicher & Schuell GmbH • P.O. Box 4, D-37582 Dassel • Germany • Tel. 49-5561-791-0 • Fax 49-5561-791538 • Internet: http://www.s-und-s.de • e-mail: sales.dispocomp@s-und-s.de

Check the blood after it's dry to make sure it's a satisfactory specimen

Allow sufficient amount of blood to soak through to completely fill the circle

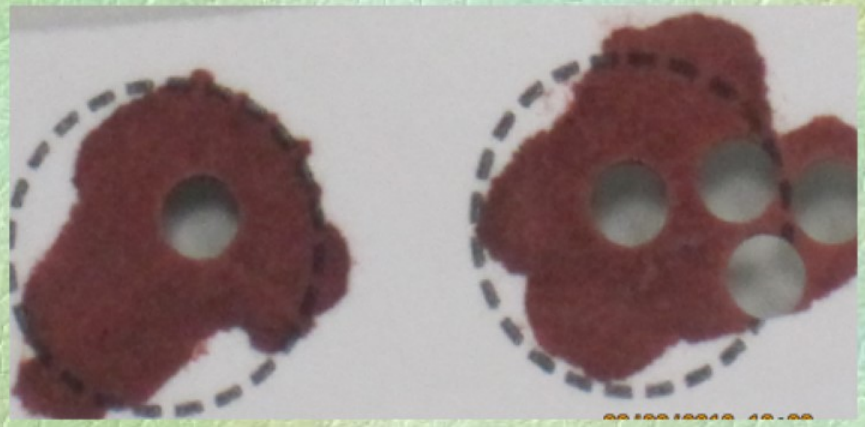
Common Problems with Newborn Bloodspot Collection

- The most common problem with newborn bloodspot screening specimens is layering of blood on the circles.

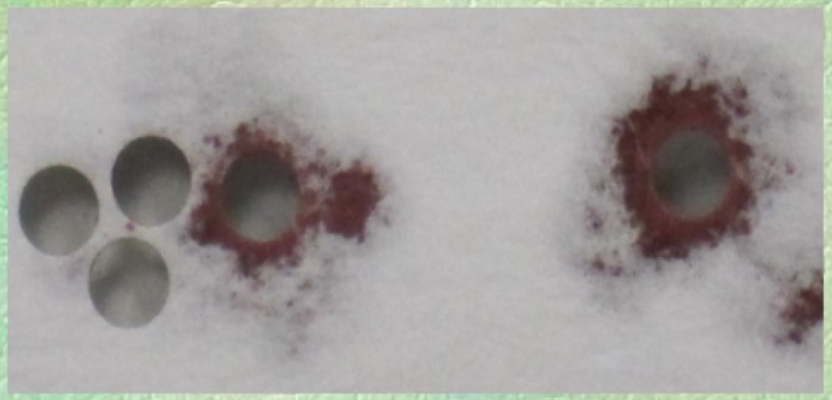
- Another common problem is not getting enough blood on the circles or not letting the blood soak through the filter paper.

- Scratching of the filter paper occurs frequently when capillector tubes are used and the blood is “colored” on the spots.

UNS 1 – Insufficient Blood to Run All Tests



From the front of the card, this specimen appears to be satisfactory.



Turning over the same specimen card shows that the blood did not saturate through the filter paper to the back of the card.

*****If a specimen looks like this, start over with a new card. Never apply blood to both sides of the card.*****

UNS 2 – Surface of Filter Paper Scratched or Abraded

- Capillary tube used during collection process abrades the surface of the filter paper.
- Rubbing the filter paper against the heel also abrades the surface of the filter paper.

*****Use direct application of a large drop of blood to the filter paper. Gently touch filter paper to the large drop of blood.*****

UNS 3 – Uneven Saturation of Blood Due to Multiple Applications

- Layers of blood can occur if more than one drop of blood are placed in each circle. Apply one large drop of blood to each circle and allow blood to soak into filter paper before moving the card.
- Blood applied to both sides of filter paper also causes layering of blood. ***Never apply blood to both sides of the filter paper.***
- Layering can also be caused by the application of excess blood, usually with a device, such as a syringe. Blood should not touch between circles.

UNS 4 – Blood Clots and Tissue on Surface of Filter Paper

The darkened areas in the spot on the right indicate the presence of clots. These clots can occur if blood sits in a capillector tube prior to application to the filter paper.

Direct application of blood from the heel is the preferred method for newborn screening specimen collection.

UNS 5 – Mottled Appearance of Blood Spot

- Foot not dried completely after cleaning with alcohol
- Something was spilled on filter paper before or after blood collection
- Separation can also occur if the baby has a history of anemia

UNS 6 – Filter paper damaged, stretched or wrinkled during collection process

Possible causes: Bending filter paper during application

Applying too much blood to one spot

Newborn Screening Results

- Results from the first screen are mailed to the hospital of birth
- Results from the first screen will also be mailed to the medical home/primary care provider, but **only** if this information is indicated on the lab slip
- If the baby has an abnormal screen, the medical home/primary care provider (PCP) listed on the screening card is called with the results. **If a provider is not listed, the Newborn Screening Follow-up Unit does not know who to contact**.
- If the hospital's on-call doctor is listed on the lab slip instead of the baby's medical home/PCP, it delays follow up and puts the baby at risk
- Abnormal screens need to be followed up ***immediately***

Electronic Results

- Hospitals and pediatricians can have access to NBS reports for their babies online.

- Please call 443-681-3900 to obtain access to reports for your babies on-line

You Can Save a Life

Prompt and correct newborn screening practices can save the life of a baby. With early intervention and treatment, even babies with serious diseases can live a long, happy life.

Educational Tools

- Newborn Screening website:

  phpa.dhmh.maryland.gov/genetics

  (Click on Newborn Metabolic Screening)

- Educational brochure for parents:

  "Your Baby's First Test"

  - ✓ Available in both English and Spanish
  - ✓ Can be printed at the hospital

Newborn Screening Program

For general questions and to request results for newborn screening specimens, please contact the Maryland State Newborn and Childhood Screening Laboratory at 443-681-3900.

For questions regarding specimen collection and abnormal results for newborn screening specimens, please contact the Maryland Newborn Screening Follow-Up Unit at 443-681-3916.