NEVADA NEWBORN SCREENING PROGRAM

The State of Nevada requires that a Newborn Screening test be ordered for all infants born within the state. The first specimen should be collected between 24 and 36 hours of age or prior to discharge, whichever comes first. Second Newborn Screening tests are required for all infants. Second Newborn Screening specimens should be collected between 5 and 10 days of age or at the first doctor visit after discharge, whichever comes first.

Specimen Collection Kit Instructions
- Gently print all information requested.
- Cold blood is not acceptable.
- Irregular results may occur on specimens collected after transfusion.

Instructions for heel stick specimen collection:
1. Place leg lower than level of the heart. Warm infant’s foot (temperature no higher than 42°C) to increase circulation.
2. Disinfect skin with non-iodine containing product and allow to air dry.
3. The labeled areas on the side of the heel in the diagram are acceptable heel stick sites.
4. Puncture the skin using a sterile lancet to a depth no greater than 2.0 mm. Use sterile gauze to wipe away the first drop of blood since it may contain disinfectant or tissue fluids.
5. Allow the second drop of blood to form by free flow of blood.
6. Touch the drop of blood to the center of the filter paper circle.
7. Fill each circle with a single application of the collection paper to a large drop of blood.
8. Do not touch blood on test area. Do not apply multiple drops to the same circle.
9. Air-dry blood spots in a horizontal position. This may take 3 or 4 hours. Project specimen from contamination while drying. Do not stack.
10. Make sure patient information on form is complete and legible.
11. Mail specimen within 24 hours of collection to:
   Nevada State Public Health Laboratory
   1660 N. Virginia St. MS 385
   Reno, NV 89557

Order additional kits by calling 775-686-1325.

Specimen Collection Precautions
- Do not touch filter paper with ungloved hands.
- Do not squeeze or milk specimen site.
- Do not write or put stickers on filter paper.
- Do not use EDTA-precipitated blood.
- Avoid contamination with glove powder.
- Do not use if damaged. Do not touch sample area.

HAVE YOU:
- Discussed NBS rationale and procedure with the parents?
- Air-dried blood spots in a horizontal position with the flap folded back?
- Checked to see that the blood spots are completely dry and protective flap is in place before submitting specimen?

This flap is for the protection of the specimen and the specimen handlers.

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Completing the revised blood spot specimen card:

The requested information on the newborn screening specimen card is critical to interpreting test results and follow up therefore **ALL fields must be filled out completely and accurately.** Demographic data should be completed before the blood is drawn to avoid contamination of the specimen. Print legibly in capital letters and neatly using black ink.

**STEP-BY-STEP INSTRUCTIONS:**

1. **KIT ID#:** This is a unique identifier number used to identify infant and to link specimens in the data system.

2. **PARENT REFUSED TESTING:** Check the box if a parent/guardian refuses the newborn screening test. Have the parent/guardian sign the Newborn Screening Test Refusal Form (Informed Dissent) and give them a copy. The original should be placed in the infant’s medical record and copies forwarded to the NV NBS Program and infant’s primary care provider. Proceed with completing the demographic information on the card as you would if blood had been collected. See Appendix 3 for Newborn Screening Test Refusal Form.

3. **ADOPTED:** Check the box if infant is being adopted and record the adoption agency or guardian’s full contact info on the newborn screening card. Record the infant’s adoptive name (if known) on the card. This expedites follow up in case of abnormal screening results and avoids calling the birth mother if she is no longer responsible for the infant.

4. **DECEASED:** Check the box if the baby is deceased. Proceed with completing the demographic information on the card as much as possible. Notify NBS FU Coordinator if an infant death occurs to prevent unnecessary notification of parents regarding subsequent screening or confirmatory testing.

5. **FIRST SCREEN, SECOND SCREEN, OTHER:** Check appropriate box to indicate if newborn screening specimen is a first or second screen. Check OTHER in situations such as 3rd screen, NICU, etc.

   **CONSENT RECEIVED:** Check Yes box to indicate that parent/guardian signed consent form to keep blood spot specimen for future research purposes. Copy of signed consent form must be provided to parent/guardian and NSPHL. Note: consent form not available yet at this time.

6. **INFANT’S NAME:** Record infant’s last name followed by first name. If no name is available at the time of specimen collection, the last name followed by “boy” or “girl” should be used. **DO NOT LEAVE BLANK.**

7. **INFANT’S BIRTH DATE:** Use a six-digit number (mm/dd/yyyy) for date of birth. For example, a birth on March 20, 2014 would be recorded as 03/20/2014. This information along with the infant’s time of birth is used to correctly interpret the screening results.

8. **INFANT’S BIRTH TIME:** Record time of birth in military time. For example, a birth at 1:30 pm would be recorded as 1330. This information is used to determine if the newborn specimen was collected within the appropriate collection timeframe and in conjunction with #7. See Appendix 8 for help with time conversions.
9- **INFANT’S BIRTH WEIGHT**: Record the birth weight preferably in grams or alternatively in pounds and ounces. This information is necessary in determining testing cutoff values and interpreting the screening results. See Appendix 9 for help with weight conversions.

10- **GENDER**: Check the appropriate box to designate newborn’s gender as male or female. This information is used to correctly interpret screening results.

11- **DATE OF SPECIMEN COLLECTION**: Use a six-digit number (mm/dd/yyyy) representing the date on which the specimen was obtained. This date establishes the parameter determining whether or not the specimen has been received within the acceptable timeframe for testing. Enzymes and metabolites begin to break down as soon as the specimen is drawn. The older the specimen when received for testing, the less likely the level of enzymes and metabolites will be accurate.

12- **SPECIMEN COLLECTION TIME**: Record time of specimen collection in military time. Screening results are based on the age of the infant at the time of specimen collection. See Appendix 8 for help with time conversions.

13- **INFANT’S CURRENT WEIGHT**: Record the current weight at the time of collection preferably in grams or alternatively in pounds and ounce. This information is necessary in determining testing cutoff values and interpreting the screening results. See Appendix 9 for help with weight conversions.

14- **PERSON RESPONSIBLE FOR SPECIMEN COLLECTION**: Record name or initials of person collecting the specimen. This information may be used for quality assurance activities such as staff retraining in proper specimen collection especially in unsatisfactory specimens resulting in repeat specimen collection.

15- **MEDICAL RECORD NUMBER**: Record the infant’s medical record number established by the birth hospital. This information is used for identification and reference purposes.

16- **SINGLE BIRTH**: Check appropriate box to indicate single birth. **MULTIPLE BIRTHS**: Check appropriate box for multiple births, circle A, B, C, D, etc. to record birth order. For example, birth order is important if baby is one of a set of multiples such as twins, triplets, etc. Names alone may not be enough to link multiple specimens in the data system.

17- **RACE**: Check all that applies for one or more of the 5 racial categories. As well, check box to indicate Hispanic or Non-Hispanic. This information is used to correctly interpret testing results and is also useful for profiling disorders and gene variations by ethnicity.

18- **FOOD SOURCE**: Check appropriate box for infant’s food source in the last 24 hours. Some testing methodologies are impacted by feeding time.

19- **GESTATIONAL WEEKS**: Record weeks of gestation at time of birth and **NOT** the current age. Gestation is the period of time between conception and birth and measured in weeks. This information is important as it directly affects the medical treatment plan for example-infants born premature.

**MECONIUM ILEUS**: Check appropriate box for Meconium Ileus or other bowel obstruction.
NICU/SPECIAL CARE NURSERY: Check appropriate box if NICU baby.

TRANSFUSION: If the infant has had a transfusion, check the box and record the date of the most recent transfusion. Transfusions may require repeat testing and can invalidate tests results in hemoglobinopathies and galactosemia.

20- BIRTH HOSPITAL NAME/CODE: Record full name of birth hospital and assigned hospital code. This information is used to determine where the 1st screening results are to be sent, helps identify a baby from another born on the same day with the same last name, and as a reference source for additional information as needed.

HOME BIRTHS- Midwives or others in attendance of a home birth are responsible for specimen collection or alternatively make arrangements for specimen collection within the appropriate time frame. Record “HOME” in this field on the specimen card.

21- COLLECTION/SUBMITTER FACILITY: Record the full name and address of the collection facility or submitter (this should be the birth hospital or midwife on all initial newborn screens) and assigned code. Same principle as stated in #20.

22- PROVIDER/CLINIC NAME: Record full name (last, first) or clinic name and address of the primary care physician that will be responsible for the infant AFTER discharge. This information distinguishes providers with the same name and the clinic where provider is located. Do NOT list the physicians such as Hospitalist or Neonatologist who cared for the infant in the hospital. If the infant is in NICU, the hospitalist/birth unit may be listed as the physician-of-record and assumes that responsibility until a provider accepts care of the infant. Please ensure that the provider’s information is accurate and complete for rapid follow up of abnormal screening result(s).

23- MOTHER/GUARDIAN’S INFORMATION: Record mother’s last name followed by first name. As well, record mother’s maiden name. For single mothers, the last name and maiden name may be the same. This information is used for identification/linking purposes. Record mother’s date of birth (mm/dd/yyyy), current address, phone number including area code, and emergency contact number including area code. Record father’s full name and phone number including area code. If infant is going to be released at birth to adoptive parents or guardian, provide contact information for them—full name, phone number including area code, and address. This information is important and critical for prompt follow up on infants in need of retesting or diagnostic testing.

Completing the miscellaneous or single blood spot specimen card:

Miscellaneous or single specimen cards are used as replacement for inadequate specimens, recall specimens, or when the second part of a double or original kit issued to the parent at the hospital/birthplace has been lost.

1- All data fields must be completed. Refer to step-by-step instructions.
2- Check the box to indicate if this is a first or second screen or other.
3- Keep in mind the kit number on the single specimen card will not be the same as the original kit number. For linking purposes, enter the original kit number of the baby’s initial screen if known
under OTHER or on the left edge of the card. If need be, call the hospital nursery to ask for the original kit number.

**REMEMBER:** Double check that ALL fields are complete, accurate, legible, and quality of the blood spots prior to being sent to testing laboratory.

**Specimen collection:**

1. To prevent specimen contamination, do not touch any part of the filter paper circles before, during, or after collection. Multiple agents can contaminate filter paper.
2. Identify infant and match with correct screening kit. Make sure to collect the correct kit part (1, 2, and 3) depending on which specimen is being collected.
3. Complete all demographic data before proceeding to collection.
4. Observe universal precautions.
5. Capillary blood obtained from a heel lance is the preferred specimen. Cord blood is not a satisfactory specimen as the infant’s biochemistry will not be reflected. Specimens obtained from peripheral or central lines are acceptable if they are flushed of parenteral nutrition or antibiotics. Blood from an intravenous stick is acceptable as long as it does not clot and can be applied to the filter paper directly.
6. It is essential to open a capillary bed to obtain sufficient blood. The most effective method is to use scalp bladed lancets manufactured specifically for heel sticks in infants. Pointed lancets are painful to the infant and make a hole rather than a small slit, greatly reducing blood flow. Under no circumstances should a lancet longer than 2.0 mm be used on infants weighing less than 2,500 grams.
7. As per your institution’s protocol, heat infant’s foot if necessary in warm water, towel, or chemical pack. Heat source should not exceed 42 degrees centigrade and should not be left in contact with skin for a prolonged period.
8. Select a lance site on the infant’s heel (see diagram), cleanse with alcohol and air dry. Hold infant’s limb lower than the heart.
9. Lance the heel with the sterile scalpel bladed lancet. Wipe away the first drop of blood to remove tissue fluids. Do not milk the heel. If blood flow is insufficient it is better to stop and relance the heel.
10. Allow sufficient blood to collect on the heel to fill each circle by a single application to the filter paper. Do not use capillary tubes or other collection devices. Apply blood only to one side of the filter paper (it doesn’t matter which side is used). Blood should soak all the way through the filter paper so that the blood spots look similar on both sides. Complete, even saturation of the entire circle is essential for accurate testing. Neatness doesn’t count.
11. It is important not to superimpose blood drops on top of each other. Let each drop touch the paper about 1/8 inch away from each other. This may prevent layering and uneven saturation, one cause of false results.
12. Collect the blood in all **five** circles. A minimum of three circles is necessary to complete the screening battery. If there are problems with sufficient blood flow, it is better to fill three circles completely than to fill five circles inadequately.
13. After circles are filled, the foot should be elevated above the heart and a sterile gauze pad or cotton swab pressed against the puncture site until the bleeding stops. Bandages should be avoided as they may irritate sensitive skin.
14. Air dry specimens at room temperature for 2-4 hours in a horizontal position with the blood spots exposed. A CD holder works well. Hanging wet specimens will cause heavier red cells to migrate to the dependent end of the circle resulting in uneven saturation.

15. Do not expose the specimen to heat or humidity at any time. Do not dry on a heater, in a microwave, with a hair dryer or in sunlight. Do not place in plastic bags, leave in a hot mailbox or in a hot car; proteins and enzymes will be destroyed. Ensure that each specimen is completely dry before mailing. In hot weather, desiccant packets may be added to reduce humidity during transit.

16. Do NOT batch specimens collected over several days as infants affected with emergent disorders may die before results can be made available. Specimens can be sent in the same package, but there must be a daily mail or courier pick up for all specimens.

17. Insert dried specimens into an envelope (do not use plastic), seal and mail within 4-12 hours of collection and no later than 24 hours after collection. Weekend and holiday specimens should be stored at room temperature and sent by overnight mail or courier at the earliest opportunity. All specimens should be sent by first class or overnight mail or by courier. Specimens should be received by the Lab within 12-48 hours of collection.

18. Specimens should be documented as sent. If by a courier, a packing list should be kept and the courier should sign for pickup and delivery of specimens. This step protects the hospital from liability in the event the specimen is lost in transit.

*These recommendations conform to the CLSI publication LA4-A5.*
## Appendix 8 - Weight Conversion Chart

### CONVERT POUNDS AND OUNCES TO GRAMS

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Appendix 9. - Military Time

Military time is a concise method of expressing time used by the military, law enforcement, hospitals, and other entities. Military time uses a 24-hour time scale that makes the use of a.m. or p.m. unnecessary. Midnight corresponds to 0000, 1 p.m. corresponds to 1300, and so on.

The following table provides a convenient way to convert between military time and regular time.

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Newborn Screening Test Refusal Form

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Home Address
City
State
Zip Code

Nevada State Health Division's Bureau of Child, Family, and Community Wellness provides a brochure entitled "Newborn Screening Tests Nevada" concerning the newborn screening tests for metabolic, endocrine, hemoglobin, and cystic fibrosis disorders.

I have been informed and I understand that these tests are required by State Law for all infants born in Nevada (NAC 442.030)

I have been told and I understand that NBS detects more than 30 disorders whose symptoms may not appear for several weeks or months.

I have been told and I understand that the risk of my infant having one of these conditions is approximately 1:1000.
I have been told and I understand that untreated, these conditions may cause permanent damage to my child.

If affected and not treated, my infant may suffer serious mental retardation, growth failure, and in some cases death.

I have discussed the testing with ____________________________, M.D./R.N. He/She has explained all the risks involved if my child is not screened. I have been informed and I understand the nature of the screening and how the Screening sample is collected.

I object to newborn screening and I do not want ______________________________ screened for these conditions.

I have freely made my decision without force or encouragement from my doctor, hospital personnel, or state officials.

Signed ___________________________ Relationship ___________________________

Witnessed by ___________________________ Title ___________________________

Date ___________________________

A copy of this signed form will be provided to parent/guardian, Newborn Screening Program, 2040 W. Charleston Blvd Suite 401, Las Vegas, NV 89102, and infant's primary care provider.