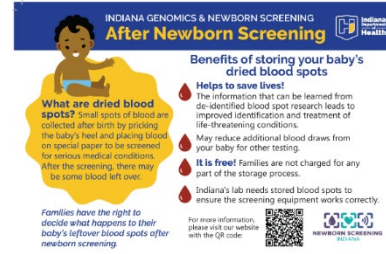
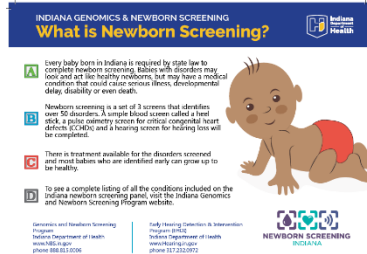


Completing the NBS Card

1 Provide family with NBS educational handouts



2 Complete front of card

- ✓ Write demographic and contact information in fields #1-17.
- ✓ Include birth hospital **and** submitting hospital names in field #9.
- ✓ Include physician name and contact (or attending physician if no PCP has been selected) in field #10.
- ✓ Write pulse oximetry and hearing screen scores in fields #18-22.

PLEASE PRINT: Complete Entire Form

Infant's Last Name [1] Infant's First Name [2] Multiple Birth (A, B, C, etc) [3] Newborn LSP Use [4]

Infant's Previous Last Name [5] Infant's Medical Record # [6]

Infant's Birthdate [7] Type of Feeding [8] Collection Date [9]

Time (Military) [10] Lactose Free [11] Soy [12] Male [13] Female [14] Unknown/Ambiguous [15]

Mother's Full Name [16] Address [17]

Hospital Name [18] Submitting [19] Birth of (Offspring) [20]

Address [21]

Birthweight [22] Ethnicity [23] Gestation [24] Gestational Age [25] Sex [26] Date of Birth [27]

Height [28] Weight [29] Pulse Oximetry Screening [30] Hearing Screening [31]

Right Hand [32] Left Hand [33]

Echo Date [34]

Submitter Label [35] Initial Screen [36] Repeat Screen [37] Print All [38] Print QMS [39]

L XXXXXX

3 Ensure family completes back of card

Ensure family has reviewed the **After Newborn Screening Handout** and

- ✓ checked the "YES" or "NO" box,
- ✓ signed their name,
- ✓ written the date.

If family is not present, tear off consent card and keep until family is able to sign.

NOTES:

- Parent(s) or legal guardian(s) must indicate whether they accept or decline participation in research & sign bottom of form.
- If participation is declined, child's DBS will be destroyed after 6 months in storage.
- If participation is accepted, child's DBS will be stored in freezer w/ humidity control & allowed to be used for research (samples will be de-identified for research use). Child's DBS will be destroyed after 3 years in storage.

23 You should have been given the brochure called "After Newborn Screening." This brochure describes how your child's blood sample from newborn screening (also called a dried blood spot, or DBS) could be used for medical research after newborn screening is complete. Please read this brochure. If you did not receive a copy, please ask your child's nurse or primary care provider for one.

As your child's parent(s) or legal guardian(s), you have the right to decide whether your child's DBS will be used for medical research after newborn screening is complete. Please read the information below. Once you decide whether your child's DBS can be used for medical research after newborn screening, check "YES" or "NO" and then sign the bottom of this form.

- It is important for parent(s)/guardian(s) to understand that participating in medical research is completely voluntary.
- There is no penalty for declining to have your child's DBS used for medical research after newborn screening.
- If you agree to have your child's DBS used for medical research now, but change your mind later, you can call the Indiana State Department of Health Newborn Screening Program & ask that your child's DBS not be used for research.

Use: Have read the brochure called "After Newborn Screening" and the information above. My/our decision about my/our child's DBS is below. My/our permission applies to this specific sample only.

PLEASE CHECK EITHER YES OR NO.

24 YES, I/we agree that my/our child's dried blood spot (DBS) can be used for medical research after newborn screening is complete. My/our child's DBS will be stored for use in future medical research. My/our child's DBS will be destroyed after 3 years.

NO, I/we decline the use of my/our child's dried blood spot (DBS) in medical research after newborn screening is complete. My/our child's DBS will be destroyed after 6 months.

If you have more questions about dried blood spots & medical research, please contact the Indiana State Department of Health Newborn Screening Program at (888) 815 - 0006.

25 Parent/legal guardian signature _____ Date _____ SN# LXXXXXX

Every NBS card needs its own consent card completed by the family, even repeats!