

Completing the NBS Card



1 Provide family with NBS educational handouts

Public Health Genetics Newborn Screening
What to Know After Your Baby Arrives

Every baby born in Indiana is required by state law to complete newborn screening. Babies with disabilities may look well and act like healthy newborns, but may have a medical condition that could cause serious illness, developmental delay or even death.

Dried Blood Spots (DBS) Screening
A dried blood spot (DBS) screen is a quick, painless, and gentle test done through a heel stick. Small spots of blood are collected after birth by pricking the baby's heel and placing blood on special filter paper. This dried, colored blood stick is sent to the newborn screening laboratory where it is tested for more than 30 tests. The screening genetic counselor, your child's health care provider will give you the results when they are available. This is usually at the first well-child visit.

Critical Congenital Heart Disease (CCHD) Screening
Critical congenital heart disease (CCHD) screen is a quick, painless, and gentle test done through pulse oximetry to measure how much oxygen is in the blood and how healthy a baby's heart and lungs are. CCHD is a heart issue that often is not detected until after birth. Some different CCHDs can be detected by pulse oximetry screening. Lack of time to have a direct heart treatment, often involving surgery, to correct them could affect a baby's life. CCHD and those that receive treatment shortly after birth, the baby has a higher chance of developing serious health outcomes, including death.

Hearing Screening
Your baby should have their hearing screened before leaving the hospital or by the time they are one month old. This hearing screen will show if your baby's hearing is normal or if they need more tests. It's quick, easy, and can be done while your baby is sleeping. Hearing loss can delay your baby's learning to speak and in language. In Indiana, a baby is born with hearing loss about every two days. If your baby does have hearing loss, there are services and resources available to help your child and family. Babies born that babies who are screened with hearing loss before they are a month old and get help by 6 months old can learn and use language like other children.

The Importance of Choosing a Pediatrician
Choosing a doctor before your baby arrives can ease your anxiety and ensure your little one gets the best care from the beginning. Be sure your birthing facility or birth provider has the name of your baby's doctor and their contact information. Your baby's newborn screening results will be shared with your baby's doctor. If your baby needs more testing, your baby's doctor will contact you to discuss next steps.

Visit more information!
Contact us!
NewbornScreening@health.in.gov

INDIANA PUBLIC HEALTH GENETICS
After Newborn Screening

Benefits of storing your baby's dried blood spots

- Helps to save lives!
- The information that can be learned from de-identified blood spot research leads to improved identification and treatment of life-threatening conditions.
- May reduce additional blood draws from your baby for other testing.
- It is free! Families are not charged for any part of the storage process.
- Indiana's lab needs stored blood spots to ensure the screening equipment works correctly.

Point your phone's camera at the QR code to access the website:

What are dried blood spots? Small spots of blood are collected after birth by pricking the baby's heel and placing blood on special paper to be screened for serious medical conditions. After the screening, there may be some blood left over.

Families have the right to decide what happens to their baby's leftover blood spots after newborn screening.

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.

3 Ensure family completes back of card

Ensure family has reviewed the **After Newborn Screening Handout** for DBS Storage consent 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.

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

Storage and Use of Newborn Screening Dried Blood Spots (DBS)

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 LXXXXX