REQUEST FOR STORAGE OF DRIED BLOOD SPOT FOR MEDICAL RESEARCH PURPOSES

State Form 55651 (8-14) / Form S

Indiana State Department of Health

If you previously did not request that your/your baby's dried blood spot be stored for medical research purposes, you can request that it be stored and saved for medical research purposes by completing and sending this form to Newborn Screening Program.

In order for the Indiana State Department of Health (ISDH) Newborn Screening Program to locate your/your son's/daughter's dried blood spot sample, certain pieces of information are needed.

Please fill out each of the lines below ***with the correct information for the person/child whose dried blood spot is being requested to be stored for medical research purposes.***

- If you are requesting the storage of your own dried blood spot sample, please fill in your own information. ***Anyone who is at least eighteen (18) years old may request his/her own dried blood spot sample to be destroyed.***
- If you are requesting the storage of your son's/daughter's dried blood spot sample, then please insert your son's/daughter's information.

Name at *birth*: ____ **Date of birth** ***(month, day, year)*****:**_________________

Location of birth *(name of Indiana hospital/midwifery where you or your child was born)*:

____

***Birth mother's* first name:** ___________________________ ***Birth mother's* last name:** ___________________________

***Birth mother's maiden name*:** _________________________

Requestor Full Name: _______________________________ **Requestor Telephone Number:** (______)_______________

Requestor Relationship to child:____

Requestor Address: ____, ________________, ________

Street **City** **State**

Purpose: Identification is required from an individual when submitting a Health Insurance Portability and Accountability (HIPAA) request regarding Protected Health Information (PHI). Below are the lists of acceptable identification that can be provided by the individual. Please provide a photocopy of one item from List A **OR** two items from List B with your request.

List A	List B
Provide photocopy of one (1) of the following items:	If you cannot provide any items from List A, provide a photocopy of two (2) of the following items:
Valid Driver License	Social Security Card
Valid State Identification	Stamped Social Security Print-out
Work Identification with Signature	Credit Card or Bank Card with Signature (backside only)
Military Identification with Signature	Motor Vehicle Registration (must be six (6) months old) – NO VEHICLE TITLES
School Identification with Signature	Valid Indiana Gun Permit
Veterans Identification Card	Rental Agreement/Lease (must be six (6) months old)
Probation Identification Card	Valid Professional License
Passport	State Agency Referral
	Employment Application (must be six (6) months old) – NO CHECK STUBS
	Employment Verification on Letterhead
	Library Card with Signature
	Previous Year Signed Tax Return – NO W2 STATEMENTS

Please sign and date the third page of this request form and fax or mail the entire completed copy to:

Genomics and Newborn Screening Program
Indiana State Department of Health
2 North Meridian St., 2E
Indianapolis, In 46204

Fax: (317) 234-2995

A letter of confirmation will be sent to the address listed on this request once the Newborn Screening Lab locates and stores your/your child's dried blood spot sample. The Indiana State Department of Health does have regular destruction schedules. If your/your child's dried blood spot has already been destroyed or it is not possible to store the dried blood spot due to its current condition, you will be notified by mail. If we have any questions regarding your request, we will contact you using the information you provided on this request. Please make sure all fields are completed in full.

If you have any questions about this form, please call the ISDH Genomics and Newborn Screening Program at (888) 815-0006.

STORAGE AND USE OF NEWBORN SCREENING DRIED BLOOD SPOTS (DBS)

Part of State Form 55651 (8-14) / Form S

NOTES:

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

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 and ask that your child's DBS not be used for research.

I/we 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 any and all blood spots collected for newborn screening.

☐ **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 three (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 six (6) months.**

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

______________________________ ______________________

Parent / legal guardian signature Date *(month, day, year)*