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Policy #001a

Iowa Department of Public Health Center for Congenital and Inherited Disorders

**Return of Residual Newborn Screening Specimens to Parent or Guardian** 

## I. Overview

This policy relates to Center for Congenital and Inherited Disorders Policy #0001 "Retention, Storage, and Use of Specimens Residual to Those Collected for Newborn Screening Services."

This policy attachment addresses a parent or guardian request to have their child's residual newborn screening specimen returned to them.

## II. Definitions

**Guardian** - means a person who is not the parent of a minor child, but who has legal authority to make decisions regarding life or program issues for the child.

**Residual newborn screening specimen** - means the portion of the dried blood spot specimen that may be left over after all activities necessary for the lowa newborn screening program are completed.

## III. Procedure

After the newborn screening testing and reporting is complete, parents or guardians may request that their child's newborn screening blood spots be returned to them at any time, as long as their child's residual newborn screening specimen has not already been destroyed.

In order to ensure that a newborn's residual specimen is released only to his or her parent or guardian, the Iowa Department of Public Health has established the following procedure:

The parent or guardian may contact the Executive Officer, CCID, at 1-800-383-3826 or by mail to Center for Congenital and Inherited Disorders, Iowa Department of Public Health, 321 E. 12<sup>th</sup> Street, Lucas State Office Building, Des Moines, IA 50319-0075, and ask for a *Request for Return of Residual Newborn Screening Specimen* form.

The parent or guardian must complete the *Request for Return of Residual Newborn Screening Specimen* form or a letter of request and submit to the Iowa Department of Public Health at the following address:

321 E. 12<sup>th</sup> Street, Lucas State Office Building, Des Moines, IA 50319-0075; Attn: Executive Officer, CCID; or fax 515-725-1760.

The form or letter must contain the following and be mailed or faxed to the Newborn Screening Program.

- Child's name at birth
- Child's date of birth
- Parent or guardian's name
- Name of child's primary health care provider
- Manner of obtaining the residual specimen registered mail or pick up at the State Hygienic Laboratory
- Photocopy of government approved photo ID of parent or guardian, or
- Notarized form indicating verification of identity

Once the request form or letter is received, the Iowa Department of Public Health will work with the State Hygienic Laboratory to process the newborn's specimen and return it to the parent or guardian in the manner selected – registered mail or pick up from the State Hygienic Laboratory in Ankeny, IA.

Any questions or for guidance on completing the request, call the Iowa Newborn Screening Program at 1-800-383-3826.

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