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Policy #004

Iowa Department of Public Health Center for Congenital and Inherited Disorders

Follow Up for Newborns Who Did Not Receive Newborn Screening at Birth

I. Overview

The Iowa Department of Public Health (IDPH) is authorized pursuant to Iowa Code 136A and Iowa Administrative Code (IAC) 641IAC 4.3 to establish a newborn screening program, and directs that all newborns born in the state of Iowa be tested for specific congenital and inherited disorders as determined by the Center for Congenital and Inherited Disorders (CCID) at the Iowa Department of Public Health and approved by the State Board of Health. Comprehensive newborn screening services including laboratory, follow-up, consultative, and educational services are provided through the Iowa Newborn Screening Program (INSP), a program of the IDPH.

INSP is a program under the CCID pursuant to Iowa Code chapter 136A and Iowa Administrative code 614 IAC 4.3. The CCID provides administrative oversight to the INSP for the Iowa Department of Public Health. The State Hygienic Laboratory (SHL) at The University of Iowa (UI) is the designated central screening laboratory pursuant to IC chapter 136A and 641 IAC 4.2. SHL tests Iowa newborns as set forth in 641 IAC 4.3 (5) and is the custodian of the residual specimens collected for newborn screening in Iowa on behalf of the INSP. Staff within the UI Departments of Internal Medicine, Pathology, and Pediatrics serve as consultants for the INSP pursuant to 641 IAC 4.3 and provide program coordination, consultation, follow up, and education activities. IDPH and the UI maintain a 28E agreement to ensure the provision of comprehensive newborn screening services for congenital and inherited disorders in the state of Iowa through the INSP.

This policy will address the process for follow up on a newborn who did not receive a newborn screening at birth.

II. Newborn Screening Code

Excerpts from Iowa Code and Iowa Administrative Code pertaining to newborn screening

136A.5 Newborn metabolic screening.

1. All newborns born in this state shall be screened for congenital and inherited disorders in accordance with rules adopted by the department.
2. An attending health care provider shall ensure that every newborn under the provider's care is screened for congenital and inherited disorders in accordance with rules adopted by the department.
3. This section does not apply if a parent objects to the screening. If a parent objects to the screening of a newborn, the attending health care provider shall document the refusal in the newborn's medical record and shall obtain a written refusal from the parent and report the refusal to the department as provided by rule of the department.

641—4.3(136A) Iowa newborn screening program (INSP). This program provides comprehensive newborn screening services for hereditary and congenital disorders for the state.

4.3(1) Newborn screening policy.

a. All newborns and infants born in the state of Iowa shall be screened for all congenital and inherited disorders specified by the center and approved by the state board of health.

4.3(2) b. Refusal of screening. Should a parent or guardian refuse the screening, said refusal shall be documented in the infant's medical record, and the parent or guardian shall sign the refusal of screening form. The birthing facility or attending health care provider shall submit the signed refusal of screening form to the central laboratory within six days of the refusal. The birthing facility or attending health care provider may submit refusal forms via the courier service established for the transportation of newborn screening specimen collection forms.

III. Definitions

Birth match – process of comparing birth certificate registration records with newborn screening laboratory records to determine if every baby with a registered birth has received a newborn screen or if a related refusal is documented

Newborn dried blood spot (DBS) screening – process of collecting blood onto an approved collection device, testing defined analytes by approved laboratory methods, and reporting results as appropriate

Refusal form – form provided by the IDPH for documentation of a parent or guardian's refusal to conduct the newborn screening on their infant

IV. Procedure

A. Birth Match A review of birth certificate registrations from the Bureau of Health Statistics at the IDPH will be matched with records of newborn screening tests from the State Hygienic Laboratory newborn screening data system.

1. The match will be done on at least a monthly basis, reviewing records posted in both systems during the month prior.
2. The match report will also include a review of records from the Early Hearing Detection and Intervention (EHDI) program.
3. The birth match report with those birth records that do not have a matched newborn screening record will be sent to the newborn screening Short-term Follow-up (STFU) program staff when completed.
4. STFU staff determines if infants were screened in Iowa, screened in another state, have a signed refusal form on file or not screened to date (missed).

B. Missed Infants

1. STFU staff will work with the facility and/or primary care provider to get infant screened as soon as possible if desired.
2. If primary care provider is not able to reach parents or no primary care provider has been provided by parents a certified letter and a letter sent via regular mail will be sent to the parent explaining a newborn screen can still be submitted if desired.

C. Refusal Forms

1. If a signed refusal form is not on record, a certified letter as well as a letter sent via regular mail is sent to the parent along with a copy of the Iowa Newborn Screening brochure and a signed copy of the refusal form explaining that a newborn screening sample will still be accepted if submitted.

2. If possible, the infant's primary care provider will be contacted to explain a that newborn screen sample will still be accepted if the family desires, an instructions will be given to the provider for collection of the specimen.
- D. Closing a case as lost to follow-up or parent does not submit a signed refusal form**
1. If STFU staff are unable to reach parents of a newborn by **three months** from attempted contact, STFU will close the case as lost to follow-up.
 2. If the parent does not submit a signed refusal form despite contact from STFU, the case will be designated as refused.