Newborn Screening Dried Bloodspot Collection Form Educational Webinar

February 28, 2017

Ashley Comer and Emily Phillips

Presenters

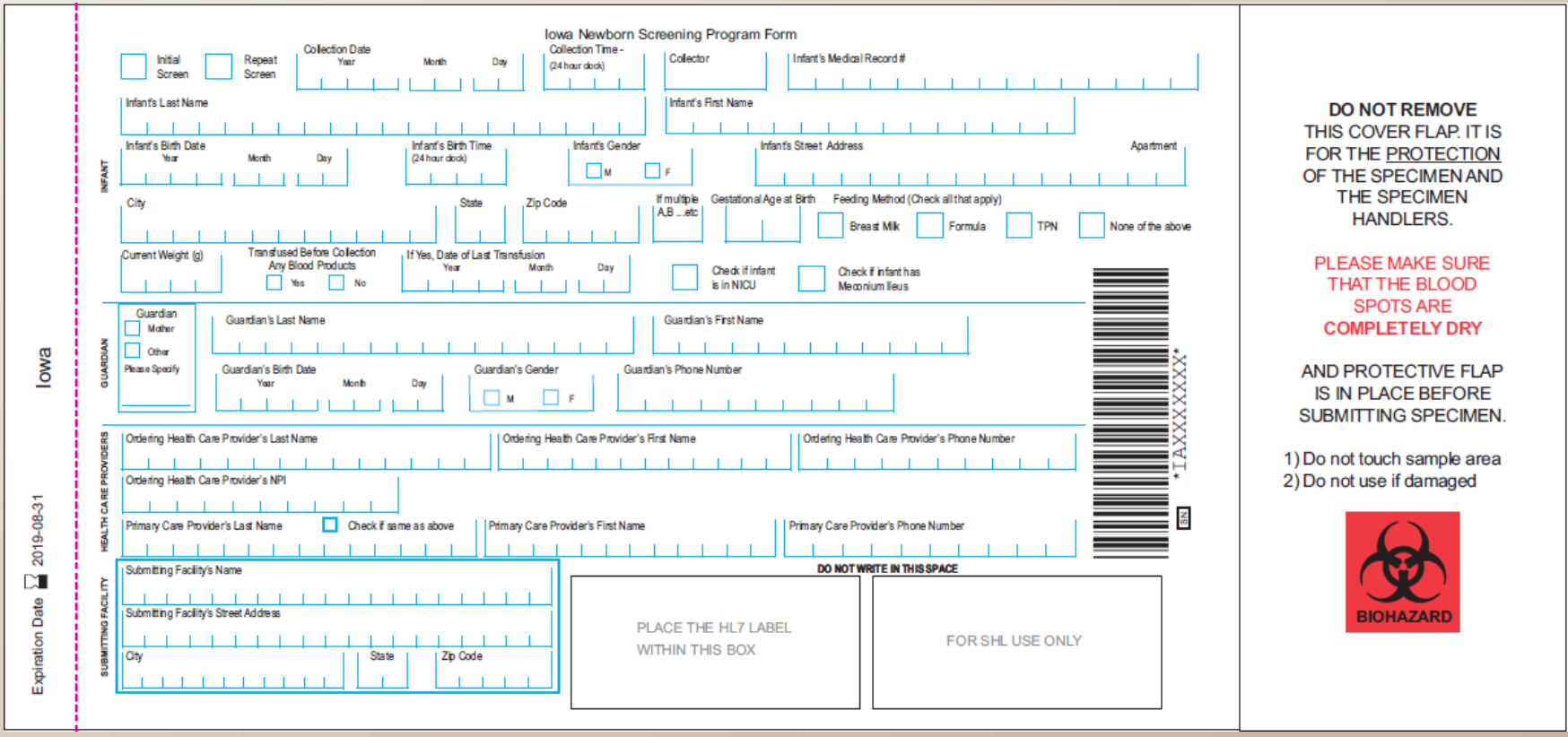
- Ashley Comer, Newborn Screening Quality Improvement Coordinator

- Emily Phillips, Newborn Screening Follow-Up Nurse

University of Iowa
Stead Family
Children's Hospital

The University of Iowa

Redesigned Card



- Overall appearance similar to current card.
- Additional fields added and arrangement of fields altered.

Education

- Before a newborn screen is obtained a parent or guardian should be educated on
  - the type of specimen
  - how it is obtained
  - disorders screened for
  - consequences of treatment and non treatment
  - Retention, use, and disposition of residual specimens

Iowa Newborn Screening Program brochures are available at 1-800-369-2229

Newborn screening educational resources are available to assist in education.

One Foot at a Time Video http://savebabies.org/video.html

It’s not just a form…It’s a baby

- Filling out the newborn screening form…
  - ✓ Accurately
  - ✓ Completely
  - ✓ Legibly

  Could be a matter of life and death

- <u>Inaccurate or missing information may adversely affect screening results and/or the ability to quickly contact the infant’s care provider in the event of an abnormal screening result.</u>

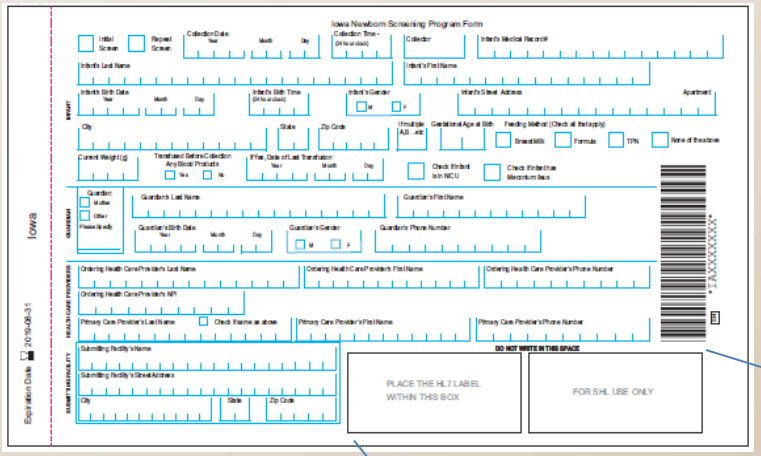
- *Any delay may put the child’s health at risk*.

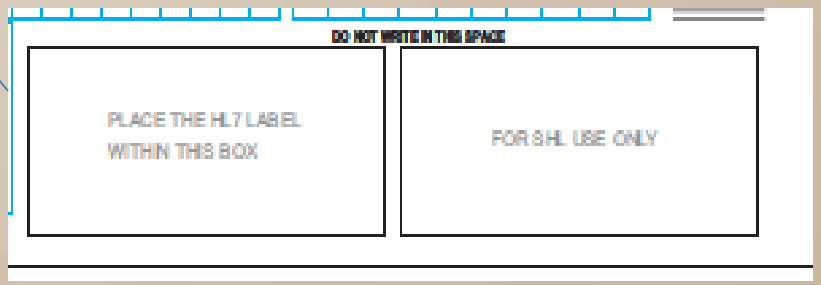
- The specimen submitter is legally responsible for the accuracy and completeness of the information on the newborn screening card.

Remember to remove 2nd ply for facility’s records.

Health Level 7 (HL7)

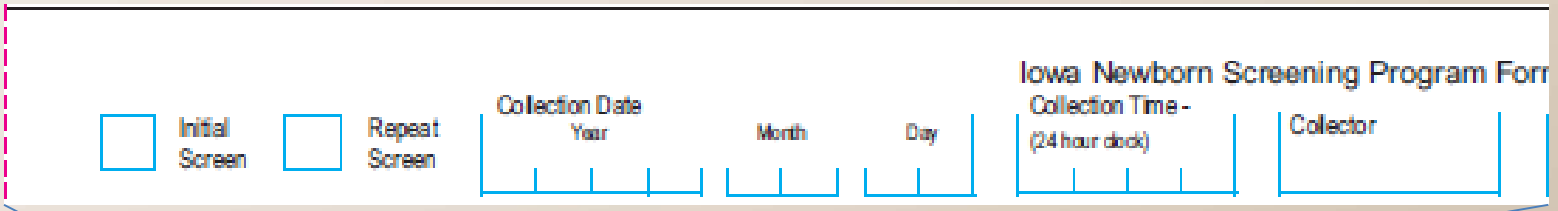
- Placement of HL7 sticker has changed

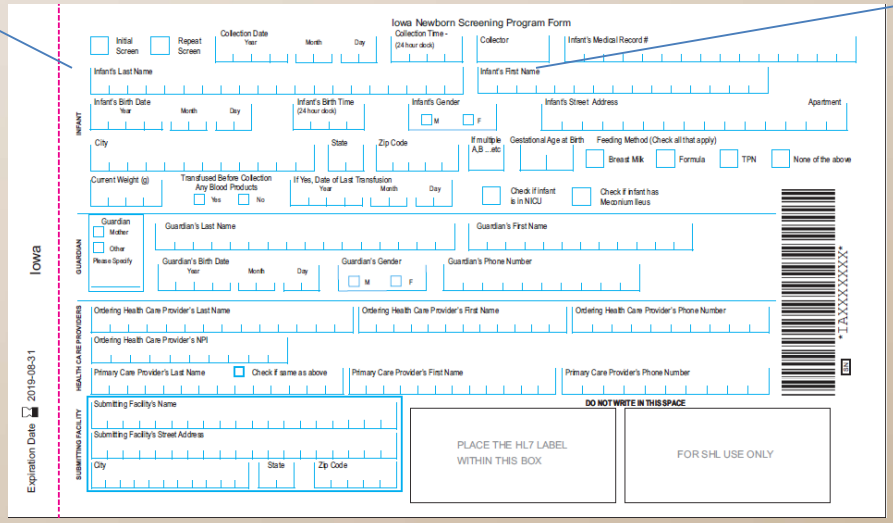




- Please do not write in the box “FOR SHL USE ONLY”

Sample Information





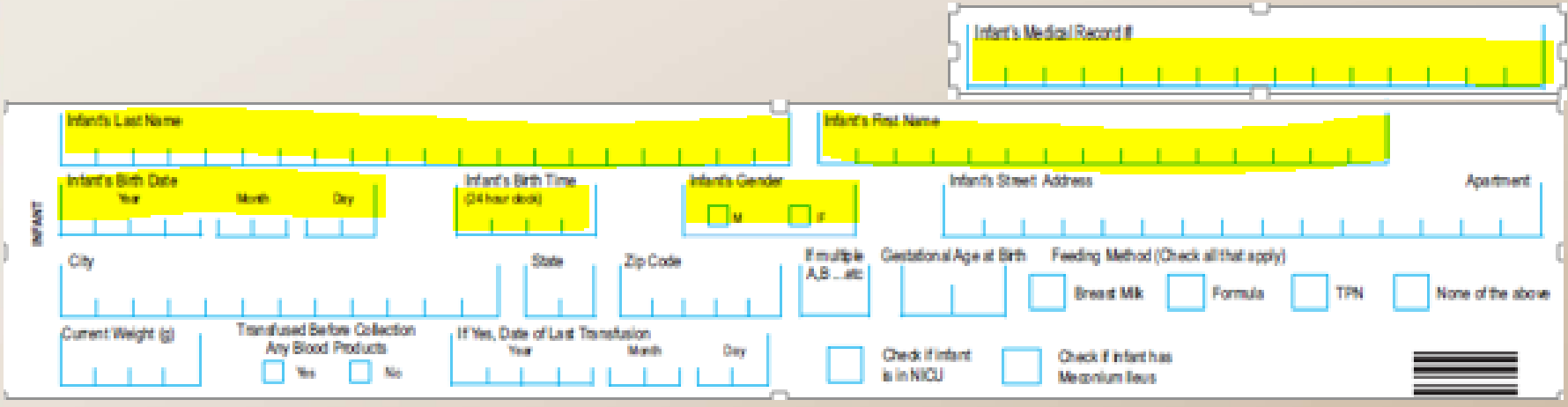
Changes

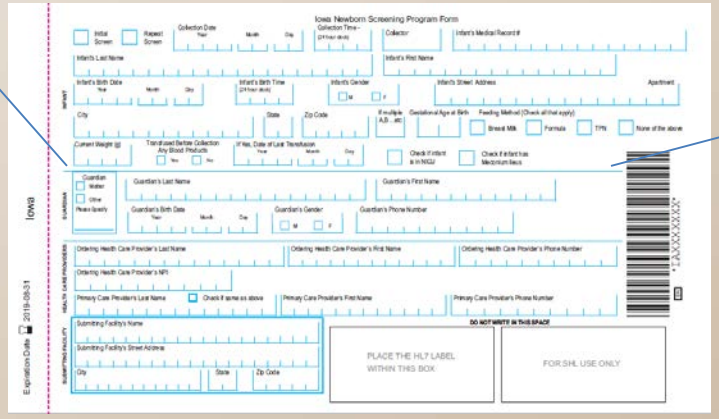
- Collection information moved to top of form
- Collection date format YYYY MM DD

Initial Screen= 1st submission

Repeat Screen= Any subsequent submissions received after the initial screen, even if 1st submission was rejected due to poor quality, early collection, etc.

Infant Information

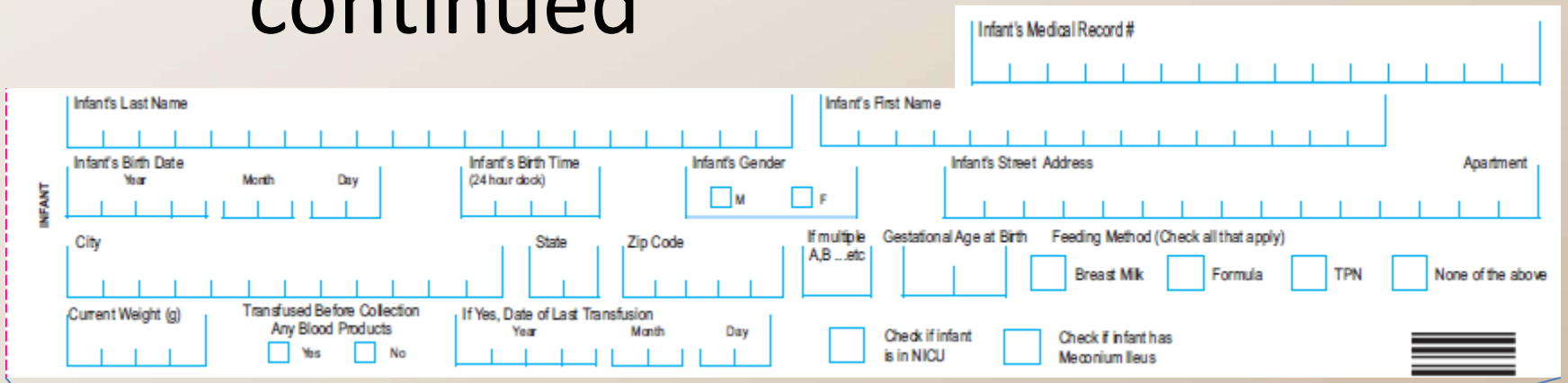


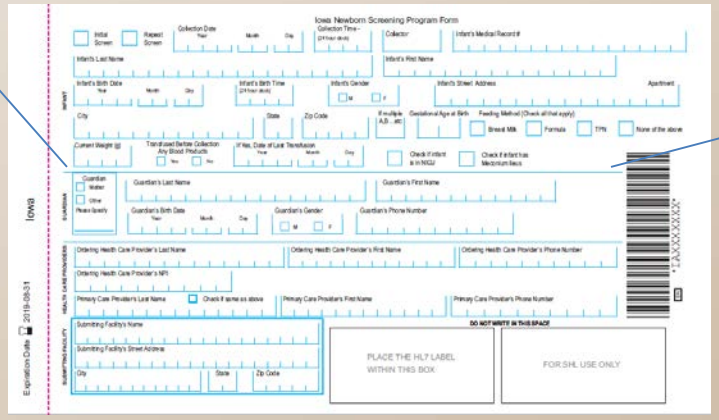


Changes

- Current card uses the term “chart number” and new form uses MRN
- DOB format YYYY/MM/DD

Infant Information continued

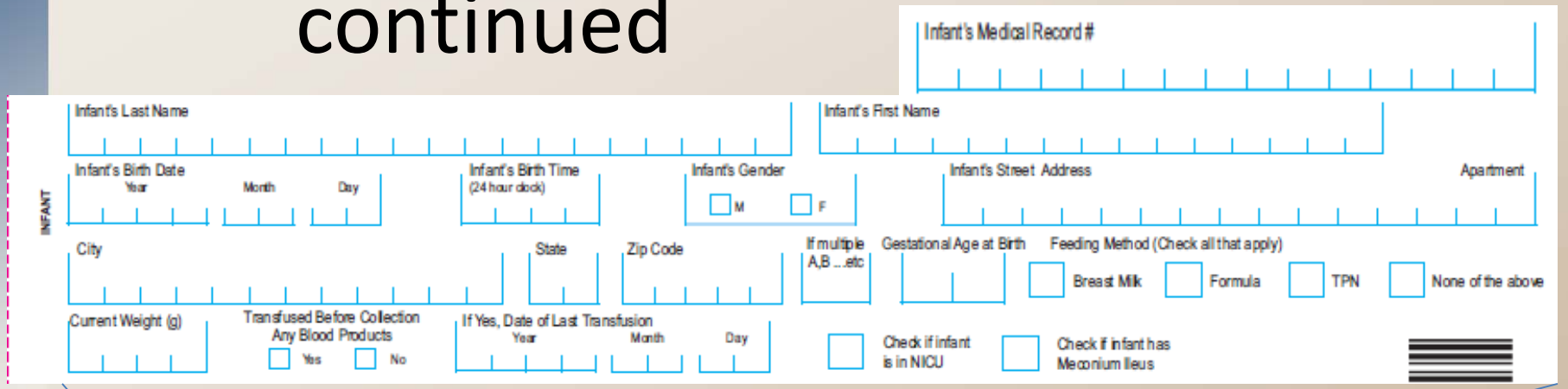


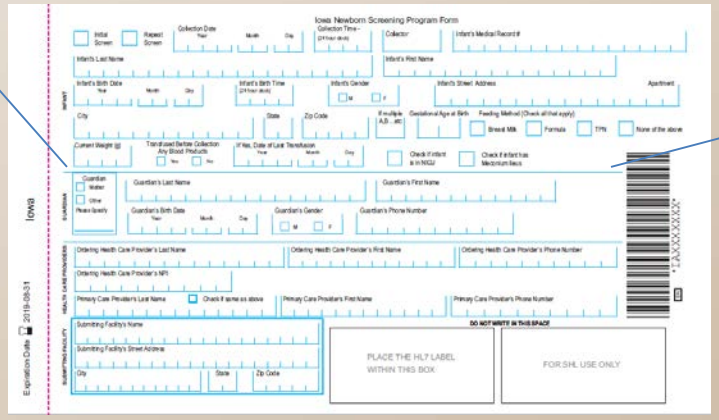


Changes

- Infant's street address
- List multiple births using A,B,C etc
  Only applicable for this pregnancy

Infant Information continued

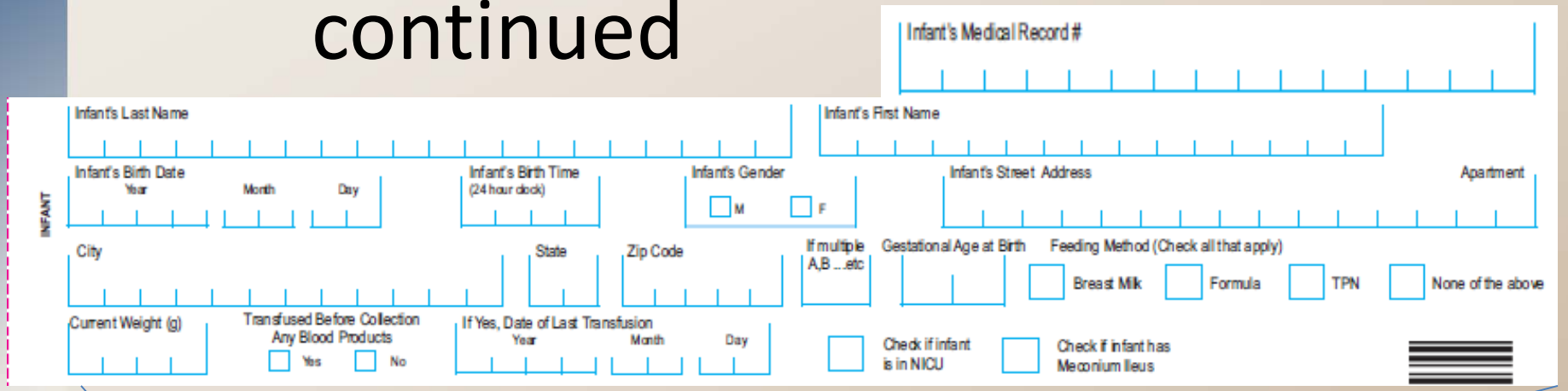


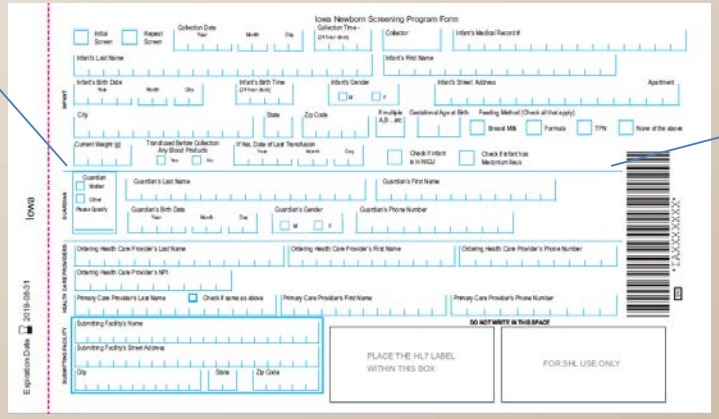


Changes

- Feeding method options changed
- Transfusion date format YYYY MM DD

Infant Information continued

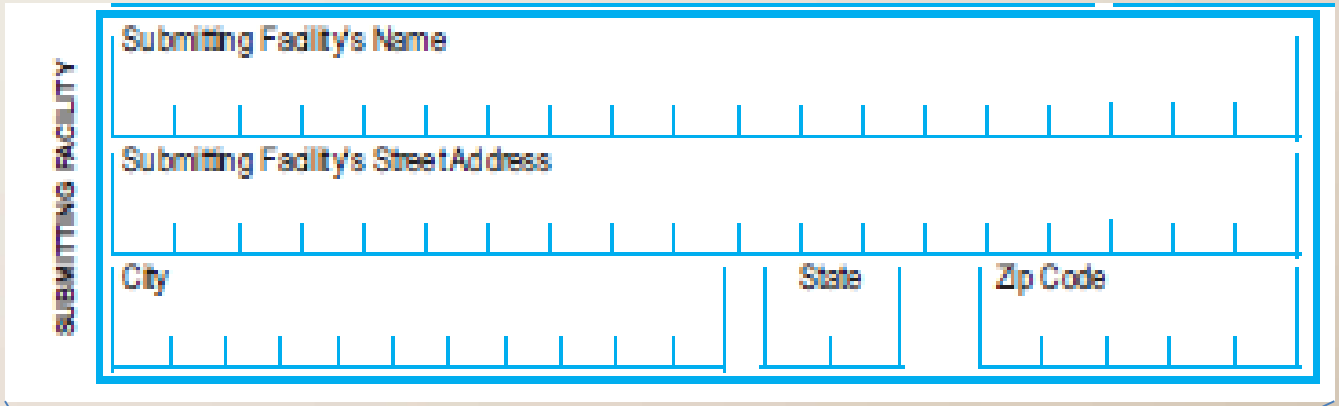


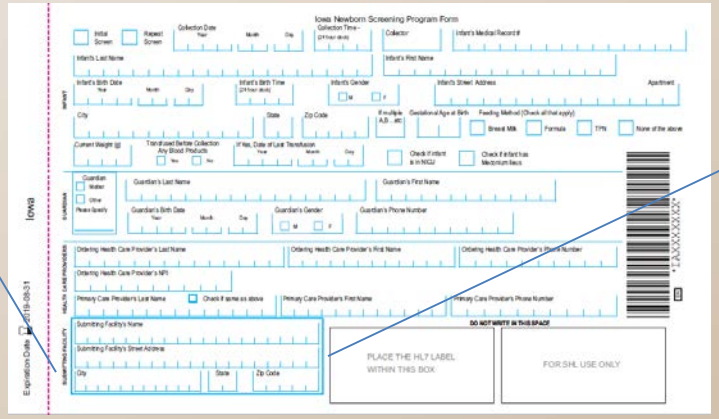


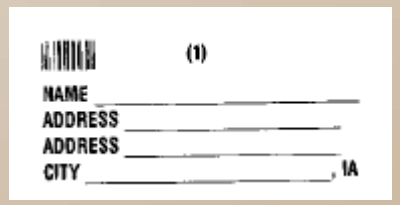
Changes

- NICU box moved
- Meconium Ileus box added

Submitter Information



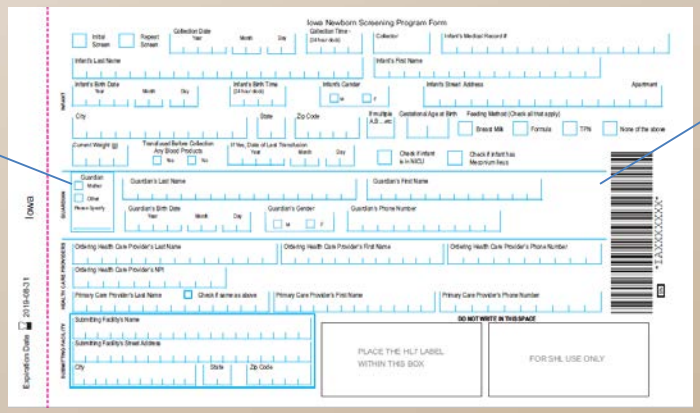




Changes

- Facility ID's are changing in our new LIMS system so this field was removed.
- Pre-printed label with submitter name and address will be provided with forms instead to accurately identify submitter.

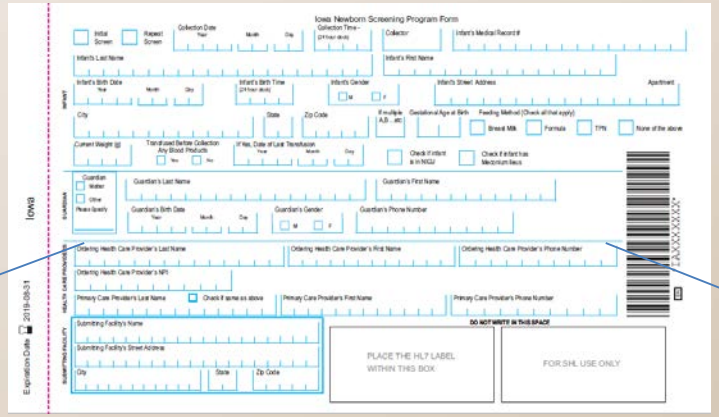
Guardian Information

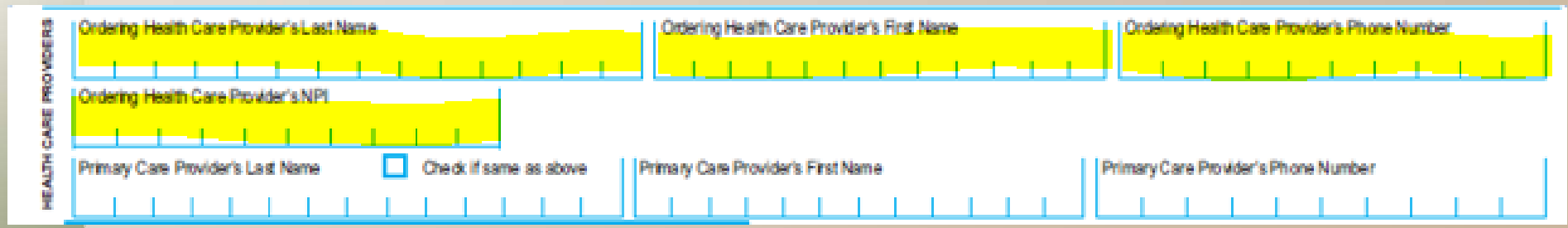


Changes

- Changed section from Mother to Guardian.
  - **If biological mother is the legal guardian, please provide her information.**
- Added Box to determine relation to infant: Mother or Other Guardian

Health Care Provider Information

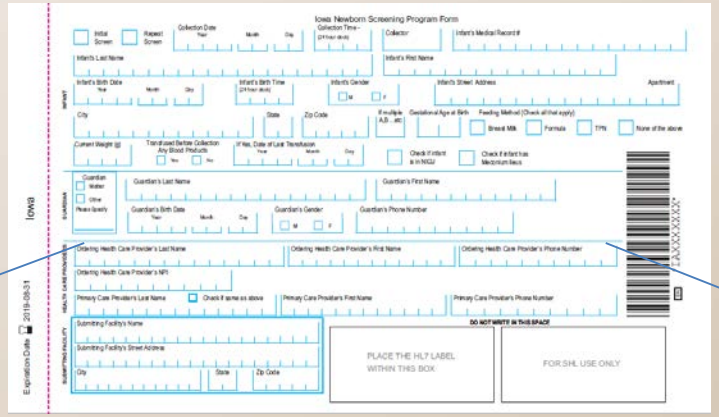


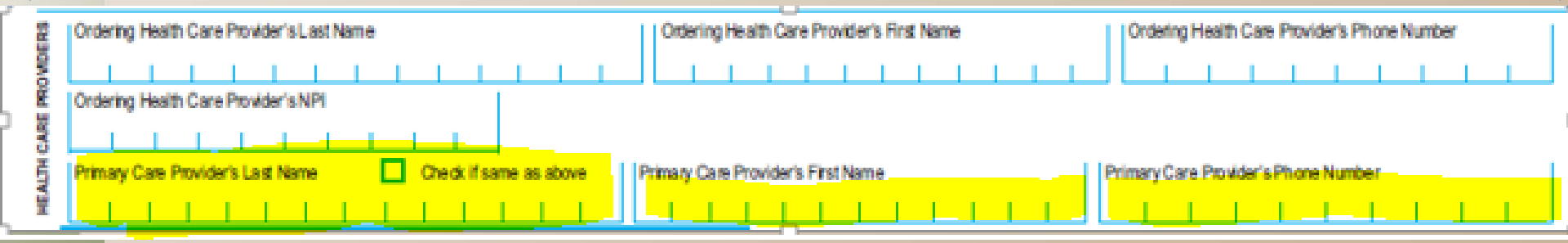


Changes

- Fields for both Ordering Health Care Provider AND Primary Care Provider
- Ordering Health Care Provider Number (NPI)
  https://npiregistry.cms.hhs.gov/

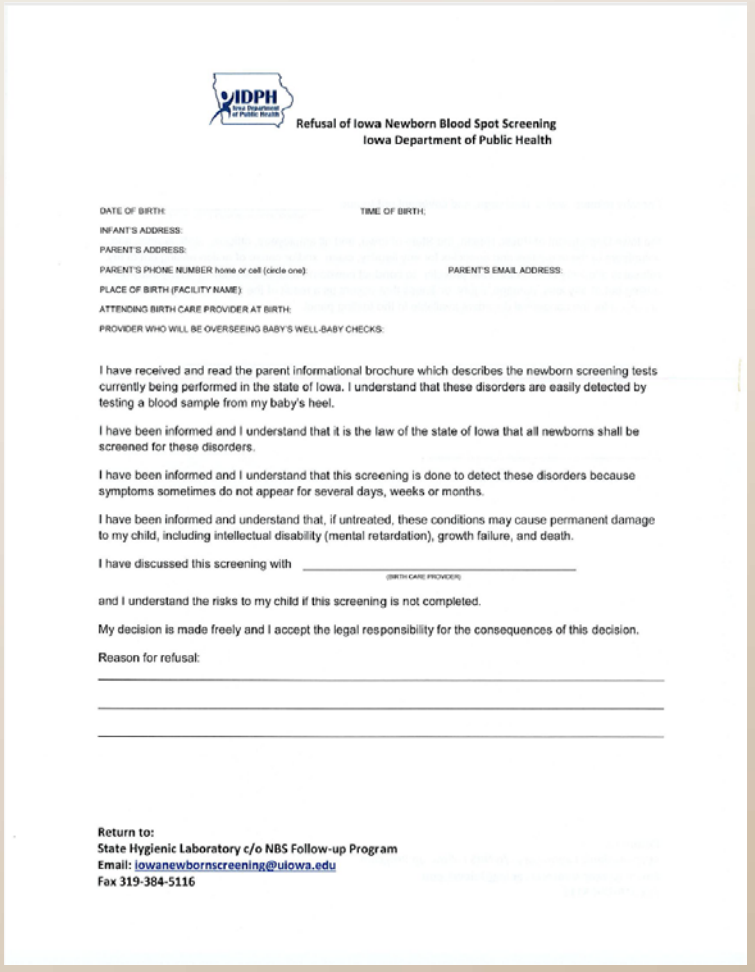
Health Care Provider Information





The NBS program requests PCP information if known at time of collection.
During education to parents about newborn screening or before the sample is collected please ask the guardian who or where they plan on taking newborn for first well check visit.

Refusals



Refusal of Iowa Newborn Blood Spot Screening
Iowa Department of Public Health

DATE OF BIRTH: TIME OF BIRTH:

INFANT'S ADDRESS:

PARENT'S ADDRESS:

PARENT'S PHONE NUMBER home or cell (circle one): PARENT'S EMAIL ADDRESS:

PLACE OF BIRTH (FACILITY NAME):

ATTENDING BIRTH CARE PROVIDER AT BIRTH:

PROVIDER WHO WILL BE OVERSEEING BABY'S WELL-BABY CHECKS:

I have received and read the parent informational brochure which describes the newborn screening tests currently being performed in the state of Iowa. I understand that these disorders are easily detected by testing a blood sample from my baby's heel.

I have been informed and I understand that it is the law of the state of Iowa that all newborns shall be screened for these disorders.

I have been informed and I understand that this screening is done to detect these disorders because symptoms sometimes do not appear for several days, weeks or months.

I have been informed and understand that, if untreated, these conditions may cause permanent damage to my child, including intellectual disability (mental retardation), growth failure, and death.

I have discussed this screening with _____
(BIRTH CARE PROVIDER)

and I understand the risks to my child if this screening is not completed.

My decision is made freely and I accept the legal responsibility for the consequences of this decision.

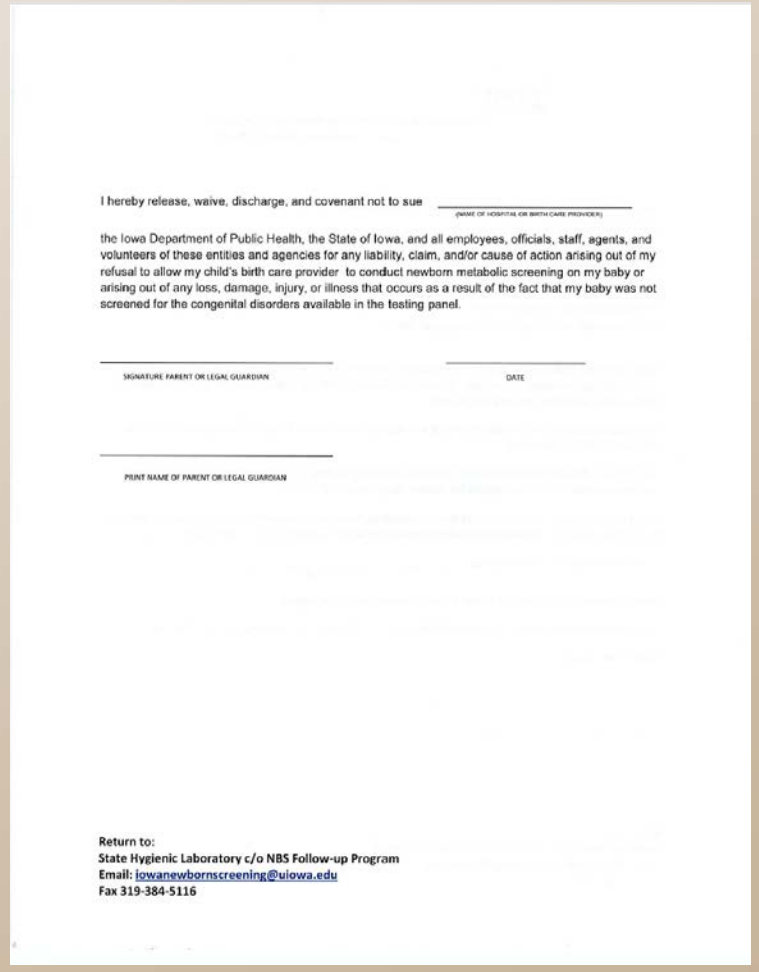
Reason for refusal:

_____

_____

_____

Return to:
State Hygienic Laboratory c/o NBS Follow-up Program
Email: iowanewbornscreening@uiowa.edu
Fax 319-384-5116



I hereby release, waive, discharge, and covenant not to sue _____
(NAME OF HOSPITAL OR BIRTH CARE PROVIDER)

the Iowa Department of Public Health, the State of Iowa, and all employees, officials, staff, agents, and volunteers of these entities and agencies for any liability, claim, and/or cause of action arising out of my refusal to allow my child's birth care provider to conduct newborn metabolic screening on my baby or arising out of any loss, damage, injury, or illness that occurs as a result of the fact that my baby was not screened for the congenital disorders available in the testing panel.

_____ _____
SIGNATURE PARENT OR LEGAL GUARDIAN DATE

_____
PRINT NAME OF PARENT OR LEGAL GUARDIAN

Return to:
State Hygienic Laboratory c/o NBS Follow-up Program
Email: iowanewbornscreening@uiowa.edu
Fax 319-384-5116

https://idph.iowa.gov/genetics/provider/newborn-screening

Contact Information

- Data entry questions or corrections:
  - State Hygienic Laboratory at 515-725-1630
- To order forms or collection supplies:
  - State Hygienic Laboratory at 515-725-1630
- Follow-up recommendations or refusals:
  - NBS Follow-up clinical staff at 319-384-5097 or toll free 1-866-890-5965
- Program and Policy questions:
  - Kim Piper at 1-800-383-3826