

NEWBORN BLOODSPOT SCREENING CHANGES

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WHAT ARE WE DOING?

- On July 1 (** June 29)
 - Changing labs from Oregon to Iowa
 - Reducing the number of routine screens from two to one
 - State will cover the cost of most expeditious shipping method
 - Screening kits will not be pre-paid
- What's not changing
 - Support from Alaska's NBS team
 - Metabolic clinic
- Expect new cards week of June 18

WHY?

Lab Change

- Iowa lab operates 24/7
- Decrease critical delays
- Turn around all results more quickly
- Improved communication with providers

of Screens

- We rarely learn anything from second screen
- More important to get good quality first specimen quickly

COSTS

- Fee will not change: \$159.50
 - But it will be *per infant* rather than *per kit* and will cover all **required** screens for that baby
 - The birth provider is responsible for collecting the first specimen and will be billed
 - Exception: babies transferred to in-state NICUs before 24 hours of life (NICU will collect/be billed)
- Fee for non-required specimens: \$100
 - If a specimen not required by algorithm is submitted, a fee will be charged

NEW CARD

Alaska

Alaska Newborn Screening Program Form

<input type="checkbox"/> Initial Screen	<input type="checkbox"/> Repeat Screen	Collection Date Year Month Day	Collection Time (24 hour clock)	Collector	Infant's Medical Record #
Infant's Last Name			Infant's First Name		
Infant's Birth Date Year Month Day	Infant's Birth Time (24 hour clock)	Infant's Gender <input type="checkbox"/> M <input type="checkbox"/> F	Infant's Race check all that apply: <input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Asian <input type="checkbox"/> American Indian / Alaska Native <input type="checkbox"/> Native Hawaiian / Pacific Islander <input type="checkbox"/> Unknown / Other		
Infant's Address			City		Infant's Ethnicity <input type="checkbox"/> Hispanic <input type="checkbox"/> Non-Hispanic
State	Zip Code	If multiple A,B...etc	Gestational Age at Birth	Feeding Method check all that apply: <input type="checkbox"/> Breast Milk <input type="checkbox"/> Formula <input type="checkbox"/> TPN <input type="checkbox"/> None of the above	Current Weight (g)
Transfused Before Collection Any Blood Products <input type="checkbox"/> Yes <input type="checkbox"/> No	If Yes, Date of Last Transfusion Year Month Day		<input type="checkbox"/> Check if infant is in NICU	<input type="checkbox"/> Check if infant has Meconium Ileus	

<input type="checkbox"/> Mother <input type="checkbox"/> Other Please Specify	Guardian's Last Name	Guardian's First Name
	Guardian's Birth Date Year Month Day	Guardian's Gender <input type="checkbox"/> M <input type="checkbox"/> F
	Guardian's Phone Number	
	Birth Mother's Last Name	

Primary Care Provider / Clinic Name	Primary Care Provider / Clinic Phone Number
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Submitting Facility's Name
Submitting Facility's Street Address <small>Apply, submitter label or print submitter name and address</small>
City State Zip Code

DO NOT WRITE IN THIS SPACE

PLACE PATIENT LABEL HERE

FOR SHL USE ONLY

XXXXXX

PerkinElmer 226 Ahlstrom LOT 111064 / 30950001 2021-03-31

INSTRUCTION MANUAL ON WEBSITE




HOW TO COMPLETE ALASKA NEWBORN SCREENING CARDS



JULY 2018



NEW WEB PORTAL: ACCESS REQUEST FORM ON WEBSITE



The screenshot shows a 'Patient Lookup' form with the following fields: Patient (text), Birth (text), Facility (text), and Pall (text). Below these are: Gender (dropdown), Birth From (calendar icon), Birth To (calendar icon), Id # (text), Chart Number (text), and Lab Number (text). At the bottom are 'Run' and 'Reset' buttons.

Download Reports

- Samples Received
- Quality Control
- Turnaround Statistics
- Facility Summary

DATA REPORTING OPTIONS

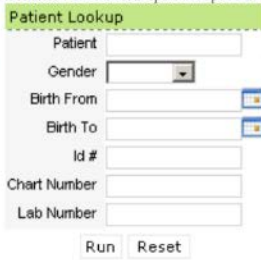
Patient Lookup

Patient Lookup provides final results in a PDF printable format. The search will return patients meeting the search criteria. When a patient's name is selected from the list a report will open that is the same as SHL's paper reports.

1. You must complete at least one field of search criteria before clicking on the **Run** button. Your options include Patient Name, Gender, Date of Birth (range), Patient ID Number, Chart Number, and SHL Lab Number. For Date of Birth, you may enter dates manually, or click on the calendar icon to select a date to be automatically entered into the field.

For further information about each field, see [Search Criteria Field Descriptions](#) on page 6.

The **Patient Lookup** screen has two purposes:



The second screenshot shows a 'Patient Lookup' form with the following fields: Patient (text), Gender (dropdown), Birth From (calendar icon), Birth To (calendar icon), Id # (text), Chart Number (text), and Lab Number (text). At the bottom are 'Run' and 'Reset' buttons.

WHAT PROTOCOL?

Baby born 6/27 or earlier (specimen collected 6/28)

- Use Oregon cards
- Can do a second screen – not clinically necessary
- All second specimens or repeats will go to Oregon
- All abnormalities will be handled by Oregon
- Accepting specimens through 12/31

Baby born 6/28 or later (specimen collected 6/29)

- Use Iowa card
- No repeats unless requested
- Initial specimens sent via courier 6/29 will go to Iowa and should be on Iowa cards

COLLECTION TIMING

- All babies need a screen at 24 hours of life
- Early collection increases FPs, especially for CF and CH
- Early collection increases likelihood of FN for critical metabolic disorders
- Testing is highly sensitive: infants do not need to have eaten “a big meal” to detect metabolic disorders
 - Even a baby who is NPO is metabolizing the nutrients mom provided in-utero by 24 hours of life
- Each birth facility has specific procedures

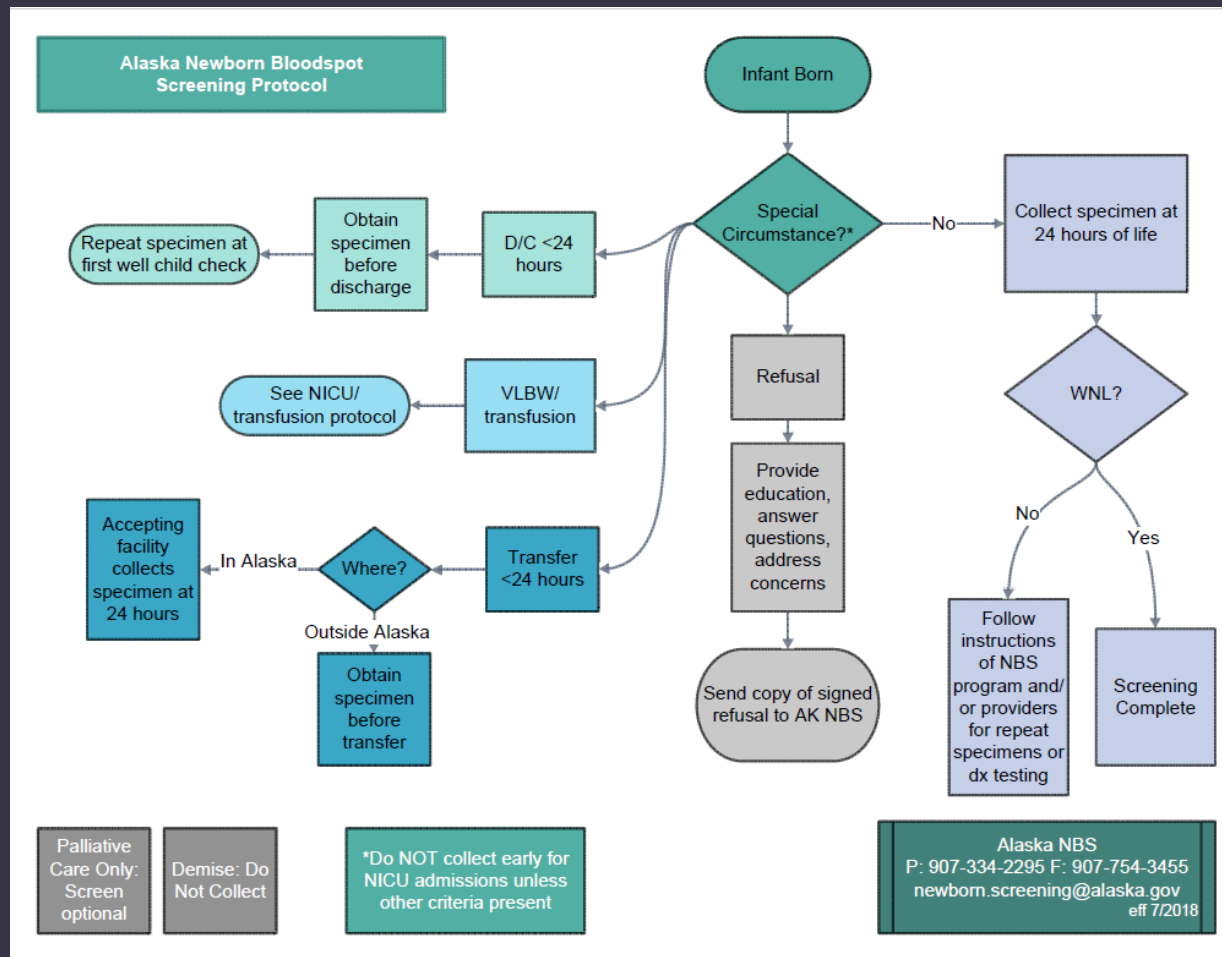
COLLECTION TIMING

- **Reasons for early collection:**
 - Baby is getting blood products
 - Baby is being discharged before 24 hours of life
 - Baby is being transferred out of state
- **Not reasons for early collection:**
 - Concern for something specific -> early collection prevents accurate interpretation
 - Baby is being given TPN/artificial nutrition -> just mark the box that indicates that
 - Baby is being transferred within Anchorage
- *Babies with an early collection (23 hr 59 min or less) will require a repeat*

WHAT HAPPENS IF...

- We send an Oregon card to Iowa?
 - Iowa will treat it as any other specimen so long as the card isn't expired
 - You will be billed by Iowa, and we will not credit the cost of the pre-paid card
- We send an Iowa card to Oregon?
 - Please don't – do not open the package of Iowa cards until the date specified
- I am concerned about something, even though the first specimen was normal?
 - Please *do not* send in another specimen
 - This will no longer be acceptable under regulations & you will be billed
 - Perform diagnostic testing if indicated

ALGORITHM: AVAILABLE ON WEBSITE



UNSATISFACTORY SPECIMENS

- This process is changing significantly
- Iowa will fax the birth facility notification of an unsatisfactory specimen the morning after specimen arrives
- It will be birth facility's responsibility to notify primary care or parents to get a recollect ASAP
- If no repeat is received within 3 days, we will contact you again
- When in doubt, recollect!

ABNORMAL RESULTS

- Called out to provider listed on card
 - May get results while infant is still inpatient
 - If family seeing someone else, that's ok as long as they've established care
 - Urgency of results impacts timing of call
- All abnormal results will come with clear instructions
 - What's off
 - What we think it is
 - What it could be
 - What we want you to do about it
 - When we want you to do it
 - Fact sheet for parents
- All babies with an initial abnormal result will get a close out letter after screening or diagnostic testing is complete

WHAT'S DIFFERENT ON THE PANEL?

- Hypothyroid
 - TSH will be measured on all babies
 - T₄ will not be tested
- Cystic Fibrosis
 - All IRT elevations will go straight to DNA
 - No waiting for a repeat specimen
 - No mutations found -> WNL
- G6PD Deficiency
 - Will not see confusing results under galactosemia anymore
- CPT_{1A} Arctic Variant
 - No change to DNA testing
 - Will be reported as homozygous for Arctic Variant only – not reporting heterozygous infants

TIMELINE (ALASKA TIME ZONE)

Baby Born

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graph TD; A[Baby Born] --> B[24 h: Specimen Collection]; B --> C[Shipping 7 days/week – exact time depends on community]; C --> D[~ 6pm: Specimens arrive at Iowa lab and start testing];
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24 h: Specimen Collection

Shipping 7 days/week – exact time depends on community

~ 6pm: Specimens arrive at Iowa lab and start testing

TIMELINE (ALASKA TIME ZONE)

~ 7 am: QA faxes sent



~ 9 am: Abnormal results called out



Real time: Complete results available
via web portal



< 48 hours after lab arrival: Most
specimens have full results available

CONSULTANTS & CLINIC

- Nothing changes about metabolic clinic with Dr. Dave Koeller and Ann Reed, RD from OHSU
- Metabolic Consultants will change
 - Pre-diagnosis: Iowa consultants
 - Post-diagnosis or unrelated to NBS: Dr. Koeller
- Alaska's specialists will continue to be primary for other results (endocrine, hematology, immunology, pulmonology), but will have Iowa's specialists for clarification and backup

LINKS & CONTACT

- <http://dhss.alaska.gov/dph/wcfh/Pages/Resources-for-Providers.aspx>
- newborn.screening@alaska.gov
- 907-334-2295 (phone)
- 907-754-3455 (fax)

If you are a provider and have not spoken to anyone from Alaska about your practice's transition to the new lab, please email or call immediately.

Thank you!