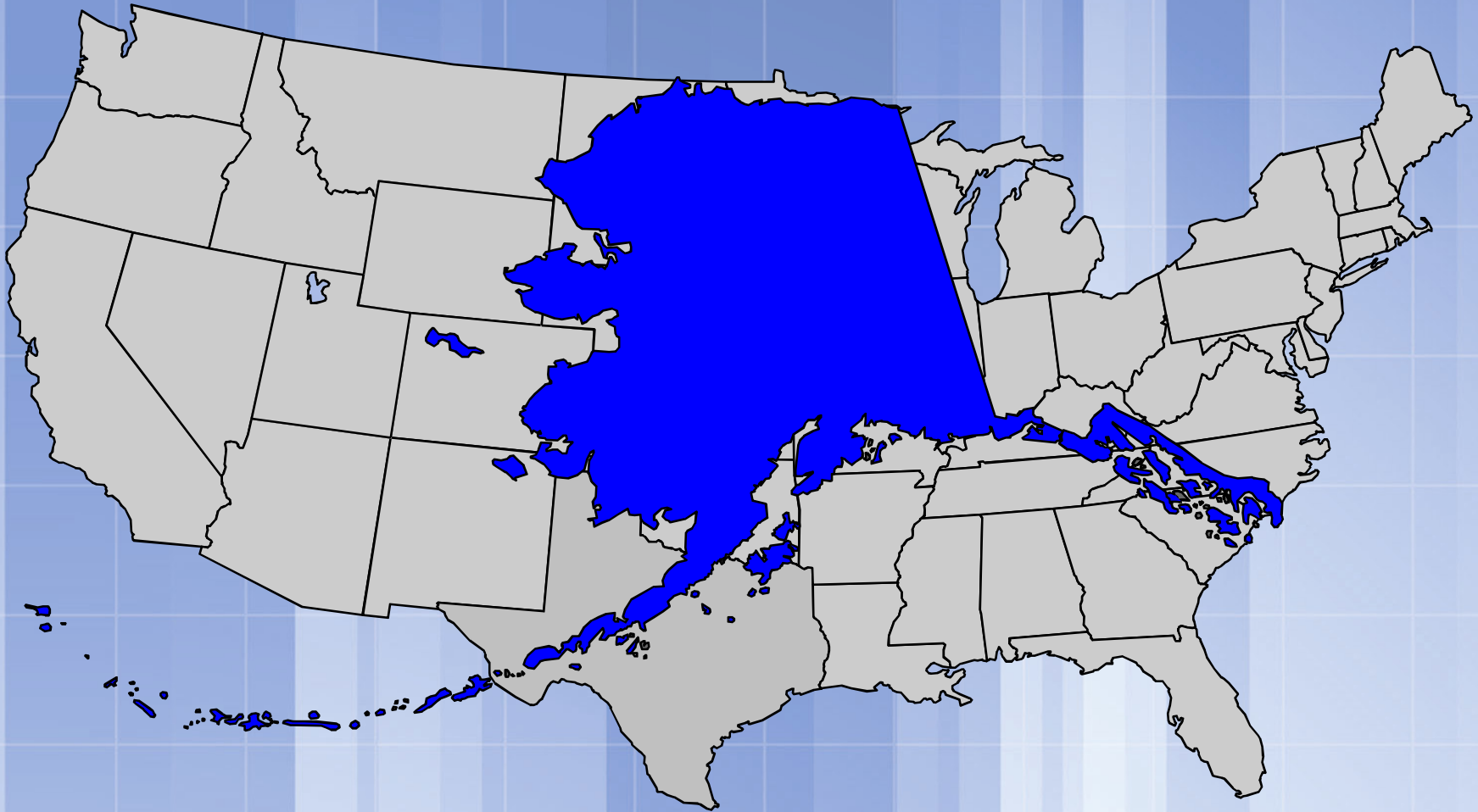


# **The Alaska EHDI and Bloodspot Database Integration Project**

**EHDI Conference  
Tuesday, March 10, 2009  
Dallas, Texas**

**Thalia Wood, MPH and Lura Dausser, MPH**

# Alaska



# HEARING SCREENING



# EHDI Database

- Database went live June 1, 2005
- Most birthing hospitals began right away to enter their newborn hearing screening data
- Screening equipment was placed in 8 public health nursing offices in areas of the state identified as having high home/midwifery center births
- Nurses from these centers were also trained on use of the database

# NBS Database

- **The NBMS program manager was also the EHDI Surveillance manager**
- **NBMS follow-up was being done through a very simple Excel spreadsheet**
- **Follow-up was done on any sample needing a repeat specimen (i.e. a bad collection or an abnormal value)**
- **Difficult to run reports from this existing database**

# Newborn Dried Bloodspot Screening



# Alaska 1<sup>st</sup> Specimen Card

RETURN TO: OREGON STATE PUBLIC HEALTH LAB  
 P.O. BOX 275, PORTLAND, OR 97207-0275  
 (503) 255-2404

**1<sup>st</sup> Specimen Card**  
**SPECIMEN AK**

\* 1 0 3 1 1 0 0 0 1 6 \*

Send Report to: PCRClinic CODE

Baby's Last Name: \_\_\_\_\_ Baby's First Name: \_\_\_\_\_

( ) Single Birth or ( ) Multiple Birth A B C D E F Code Out

Sex: M F ID Chart # \_\_\_\_\_

Birth Date: ( / / ) Time of Day: ( ) AM/PM Sex Wt: \_\_\_\_\_ Lbs. or \_\_\_\_\_ gms

Food Source:  Breast  Formula  WFO  Other \_\_\_\_\_ Check all that apply

Last 24 Hours:  Lactose Free  Soy  Cow \_\_\_\_\_

Last RBC Transfusion Date: / /

Other Factors:  Hyperbilirubinemia  None

Baby's Race:  White  Black  Amer. Ind.  Asian  Hispanic  Linnaean/Other  Asian/Pacific Islander

Mother's Last Name: \_\_\_\_\_ Full Name: \_\_\_\_\_ Mother's Birth Date: \_\_\_\_\_


Hosp. or Hosp. CODE: \_\_\_\_\_

Mother's Address-Number & Street: \_\_\_\_\_

Baby's Home Address: \_\_\_\_\_ City/State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

**DO NOT REMOVE.**  
**Fold flap over blood spots before mailing.**

  
**BIOHAZARD**

# Integration of Database

- **Decision was made to work with the EHDI database vendor to include the metabolic screening data**
- **This is also one of the goals stated in the CDC guidance for the EHDI grant and was written into the State of Alaska application for continuing funding**
- **Work began in earnest on this project in 2006**
- **Integrated database went live January 2008**



# Why integrate EHDI and NBS?

- **Assure thorough and accurate care for each child born**
- **Helps prevent children being missed**
- **Connect information “silos” that contribute to disjointed care for child and family**
- **Raise the performance bar for both programs**

# Results

- **Integrated information system for newborn screening that captured patient characteristics**
- **Serves as a cross-check for NBS, and NBS for NBHS, so all infants receive screening and follow-up in both programs**
- **The integrated system allows multiple authorized care providers to be associated with the baby's record**
- **Updates health records in real time, facilitating comprehensive care of the child.**

# Metabolic Record

Metabolic 
Patient Outcome: Disorder(s) Detected

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**Consent:** Full

**Patient Outcomes:**

Description	Status
Patient Case	Open <input type="button" value="v"/>
Metabolic Outcome	Disorder(s) Detected <input type="button" value="v"/>

**Review Case :**

Does Not Need Review

Needs Review by:

No Reviews

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**Other Factors:**

Hyperalimentation                      Transfused                      Date of Last RBC Transfusion:

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**Last Metabolic Case Note:**


no note available


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**Most Recent Specimen Summary:** 9/22/2007 5:00:00 PM

Test	Evaluation	Test	Evaluation
T4	Normal	Amino Acids	Normal
Phenylalanine	Normal	Acylcarnitines	Normal
Biotinidase	Normal	Hemoglobinopathies	Probable S Trait
CAH	Normal	CF	Normal
GALT	Normal		

# Hearing Record

**Child Information**  quick links:

**Patient: Testing, Sample (Male)**   
**Birth Cert. ID: NA Medical Record No.: jc-107**

**Patient Outcomes:**

Description	Status	Appointment	
Birth Screen	Bilateral Referral		
Outpatient	<input type="text" value="Bilateral Referral"/>		
Risk Monitoring	Not Required		
Audiological Assessment	<input type="text" value="Bilateral Referral"/>		
ENT	<input type="text" value="Required - Not Scheduled"/>	Appointment Required	<input type="button" value="edit"/>
EI	<input type="text" value="Required - Not Scheduled"/>	Appointment Required	<input type="button" value="edit"/>
HAB	<input type="text" value="Required - Not Scheduled"/>	Appointment Required	<input type="button" value="edit"/>
Contact Info	Required and Present		

**Screening Results:**

	Screen Type	Screeener	Ear	Result	Test Time	Test	In	Ov
<input type="button" value="view"/>	Outpatient Screen	Daussat, Lura	R	Refer	10/24/2007 4:23:37 PM	A ABR	M	
<input type="button" value="view"/>	Outpatient Screen	Daussat, Lura	L	Refer	10/24/2007 4:23:37 PM	A ABR	M	
<input type="button" value="view"/>	Birth Screen	Daussat, Lura	R	Refer	9/29/2007 4:22:30 PM	A ABR	M	
<input type="button" value="view"/>	Birth Screen	Daussat, Lura	L	Refer	9/29/2007 4:22:30 PM	A ABR	M	

**Assessment:**

Assessment Data  Amplification/Intervention Data

# METABOLIC JOURNEY

⊕ SCREENER PLUS

No Results



Assign Specimens



Open - Needs Review Cases

Repeat Specimen  
Required

Disorder Detected Not Yet  
Confirmed

Critical Value Not Yet  
Confirmed



Trait Detected

Confirmed Diagnosis





Recently Closed Cases

Refused

# Specimen Details

## Child Information

quick links: [select a page](#) 

**Patient:** Testing, Sample (Male)   
**Birth Cert. ID:** NA **Medical Record No.:** jc-107

### Metabolic and Genetic Specimen

#### Patient Information:

Date of Birth:	9/19/2007	Time of Birth:	12:43 PM	Race:	Black
Birth Weight:	3333 g	Birth Order:	1 of 1	Ethnicity (Hispanic):	No

#### PCP/Medical Home Information:

Send Report to PCP/Medical Home:	Address:
Doctor's Code:	Telephone Number:

#### Submitter Information:

Name:	NEYHART, JOY DO
Code:	AK3390
Address:	3268 HOSPITAL DR STE D JUNEAU AK 998017800

#### Hospital Information:

Name:	ZZZ THALIA TEST FAC
Code:	AKJOHN
Address:	2112 THALIA STREET JUNEAU AK 99801
Telephone Number:	

#### Mother's Information:

Name:	ROSE, MOTHER
Date of Birth:	4/5/1985
Address:	ANCHORAGE, AK 11111
Telephone Number:	

#### Lab Information:

Card Specimen Type:	1st Specimen	Lab Specimen Type:	1st Specimen
Kit Number:	051106324	Accession (lab) number:	20071840192

#### Specimen Information:

Date and Time of Specimen Collected:	9/22/2007 5:00:00 PM	Specimen Status:	Disorder(s) Detected
Age at specimen collection:	12 Hour(s)	Present Weight:	4025 (g)
		Transit Time:	0 Hour(s)

#### Other Factors:

Food source last 24 hours:	other not specified	Transfusion:	Date of Last RBC Transfusion:
Hyperalimentation:			

# Screening Results

## Test Results:

Alaska Resources



Test	Status	Result	Evaluation	Reference
T4	NOR	13.3 ug/dL	Normal	** Age Adjusted **
Phenylalanine	NOR	< 200 uM	Normal	Normal < 200 uM
Biotinidase	NOR	Has Color	Normal	Normal Has Color
CAH	NOR	24.08 ng/mL	Normal	** Age Adjusted **
GALT	NOR	Fluorescence	Normal	Normal=Fluorescence
Amino Acids	NOR	Normal	Normal	Normal
Acylcarnitines	NOR	Normal	Normal	Normal
Hemoglobinopathies	FAS	FAS	Probable S Trait	Normal = FA
CF	NOR	21.5 ng/mL	Normal	** Age Adjusted **

[Return to Metabolic Tab](#)

# Benefits

- **Web-based information system for EHDI and NBS screening**
- **HIPAA compliant system that meets the needs of both programs**
- **Pulls bloodspot test data directly from Oregon Public Health Lab**
- **Imports hearing screen data from hearing screening technology**



# Challenges

- **Access to specific arenas of care while maintaining confidential and secure records**
- **Developing appropriate access rights for the application**
- **Distinguishing case notes specific to the arena of care**
- **Consent to each program**

# Another Challenge: Getting Patients to the Clinic for F/U



# Lessons Learned

- **Metabolic screening is often downloaded before hearing screening results are entered**
- **This results in a large unassigned specimen queue**
- **Identifies which institutions need additional education**
- **Changes made as we went to enhance the search capabilities**

**Another Lesson Learned: Twins present particular problems for matching**



# Public Health Implications

- **CDC EHDI grant**
- **Addition of PCP could ensure patient has “medical home”**
- **Decrease Lost to Follow-up and Missed babies for EHDI**
- **Ensure all babies are screened for both hearing loss and metabolic and genetic conditions**

# Contact information

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**Lura Daussat, MPH Program Coordinator, OZ  
Systems, [ldaussat@oz-systems.com](mailto:ldaussat@oz-systems.com) or 888-  
727-3366 ext. 722**

**Thank you!**