

Colorado's Integrated Data System: *one state's approach to a comprehensive health information exchange for short-term and long-term follow-up*

Erica L. Wright, MS, CGC
Certified Genetic Counselor, Instructor



Children's Hospital Colorado

Affiliated with



University of Colorado
Anschutz Medical Campus

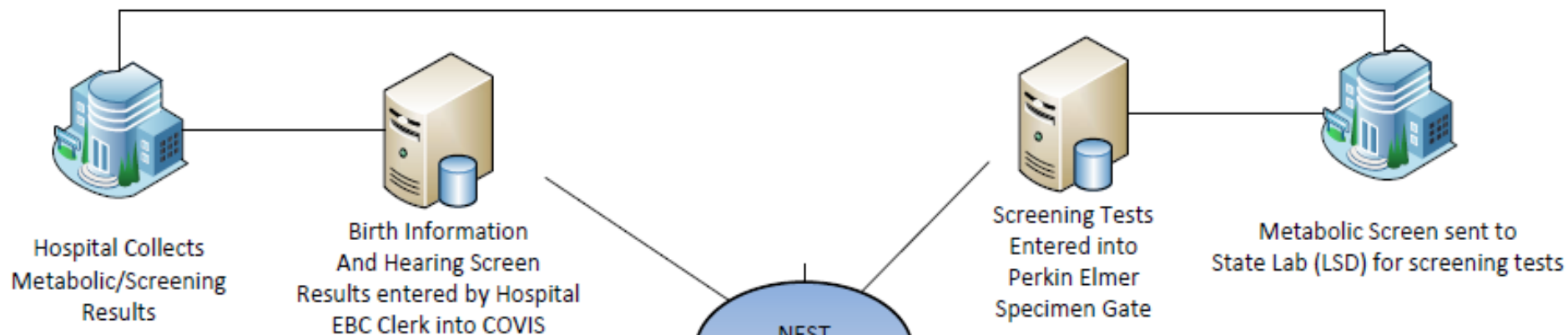
School of Medicine

History of Colorado's Integrated Data System (IDS)

- Developed in 2000 through an Early Hearing Detection and Intervention (EHDI) grant to develop electronic tracking system for newborn hearing and newborn blood spot screening at the Colorado Department of Public Health and Environment (CDPHE).
- Formally known as CHIRP (Clinical Health Information Records of Patients)
 - Multiple local applications
 - CDPHE Hearing/NBS, Metabolic, Sickle Cell
 - Became web-based in 2010 and renamed IDS.
- Awarded “Effective Follow-up in Newborn Screening” grant in 2009 from HRSA.

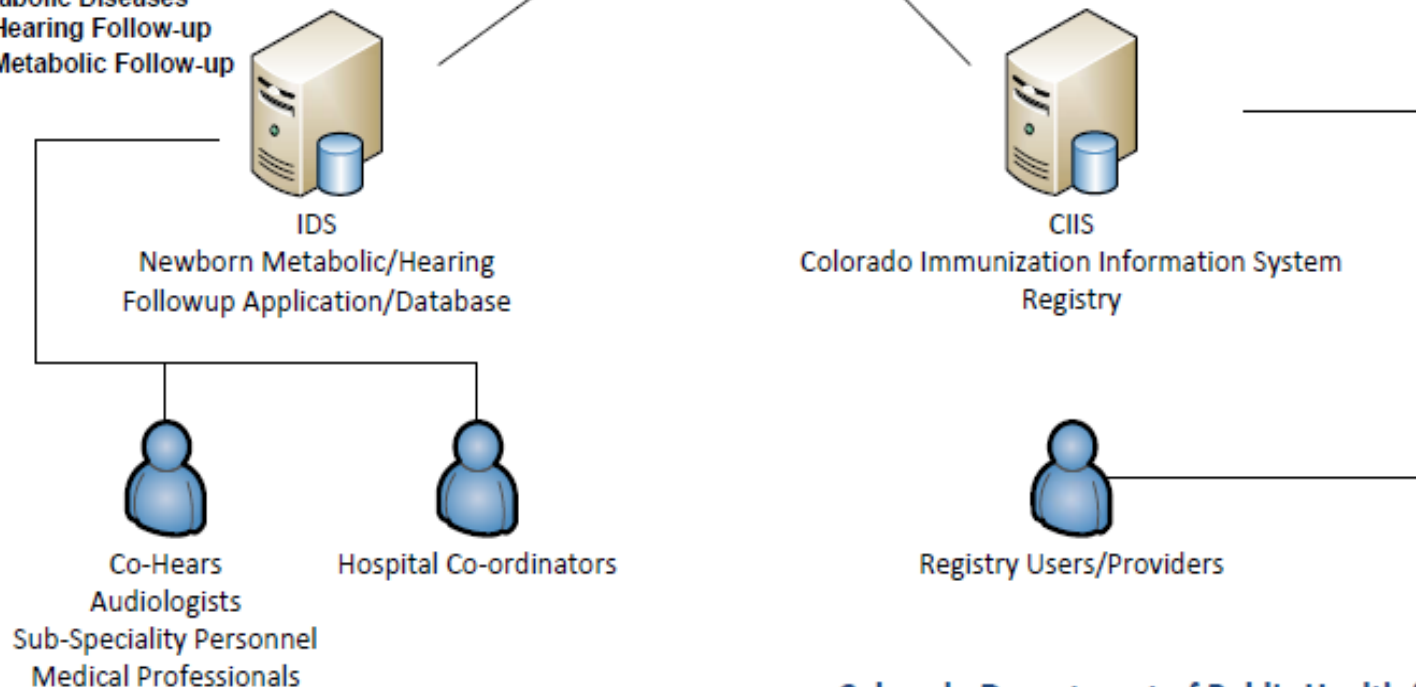
Effective Follow-up in NBS

- Colorado was one of 4 grantees awarded
- \$1,200,000, 3 year grant
- Joint effort of CDPHE and Children's Hospital Colorado Inherited Metabolic Diseases (IMD) clinic
 - CDPHE PI: Chris Wells, PhD
 - IMD clinic PI: Janet Thomas, MD
- ***In summary, all goals focused on improvement and further development of IDS for both short-term and long-term follow-up.***



Sub-Specialities:

- CHC - Sickle Cell Clinic
- CHC - Inherited Metabolic Diseases
- CDPHE - Newborn Hearing Follow-up
- CDPHE - Newborn Metabolic Follow-up



**Colorado Department of Public Health & Environment
Public Health Informatics
Metabolic/Hearing Screening Architecture**

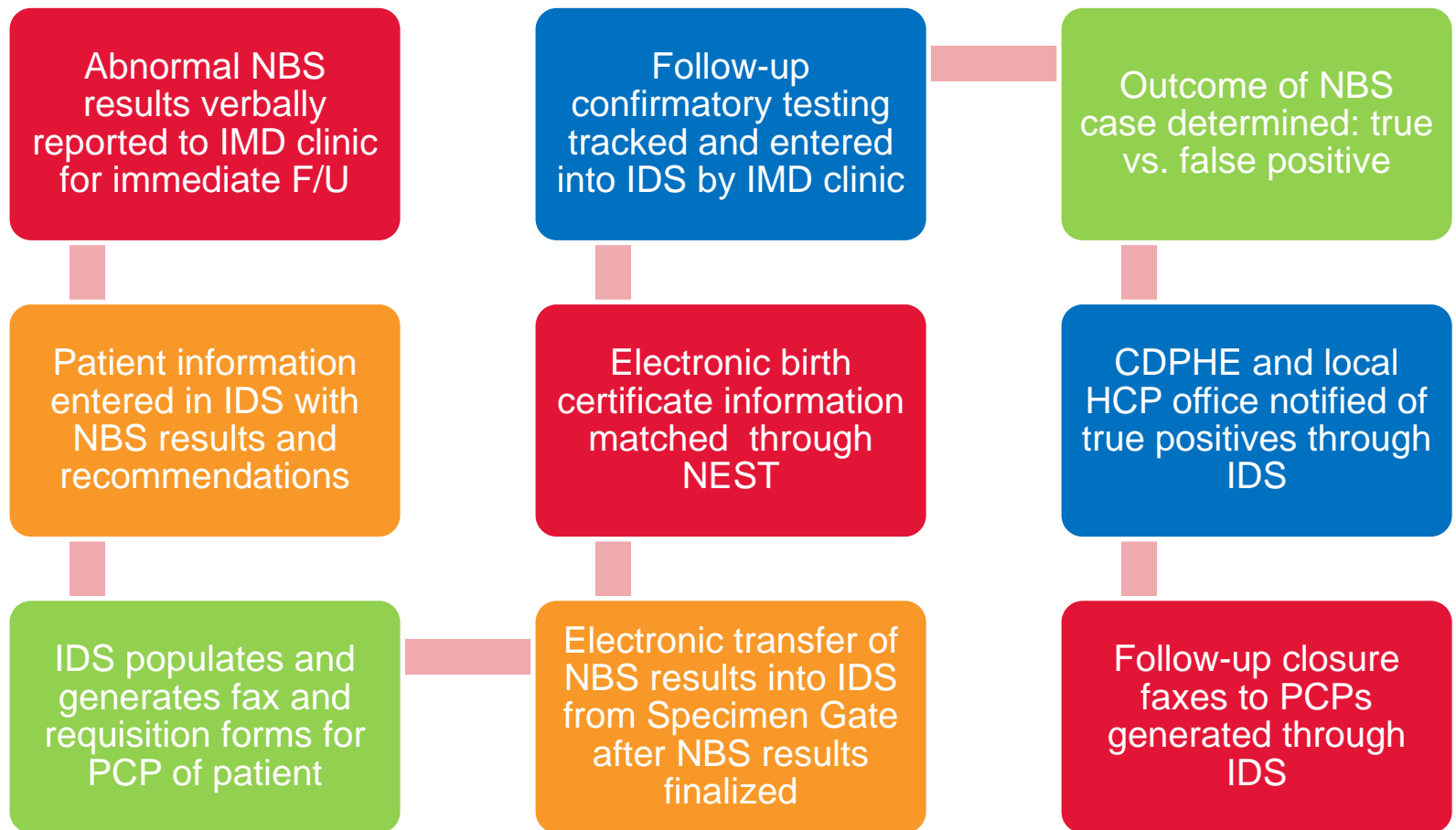
Metabolic Application

- Extensive clinical and laboratory database in collaboration with the staff of the Inherited Metabolic Diseases (IMD) Clinic at Children's Hospital Colorado/University of Colorado Denver.
- Information populated by multiple applications:
 - IMD clinic
 - Health Care Program for Children with Special Needs
 - Vital Records (electronic birth certificate)
 - CDPHE's NBS lab via Specimen Gate.
- Newborn Evaluation Screening and Tracking (NEST)
 - Centralized database and integration application

Short-term follow-up (STFU)

- IMD clinic utilizes IDS to track abnormal newborn screens, recommendations, follow-up studies and outcome.
- Only patients with abnormal metabolic screens can be viewed by the IMD clinic.
- Report function
 - Query open NBS cases
 - Track timeliness of follow-up
 - Provide quarterly/yearly updates to CDPHE
- Two-way communication
 - CDPHE follow-up team
 - Local public health nurses

Workflow





IMD Option Menu



Pending System Messages

Tuesday, April 23, 2013

- Main
- Family
- Add New
- Address
- Contact Information
- Birth
- Race
- IDs
- Providers
- Communication
- Notification
- Diagnosis
- Metabolic Screen
- Metabolic Evaluation
- Developmental Test
- Developmental Outcomes
- Outcome Measures
- Specialty Evaluation
- Urgent Emergency Care
- Metabolic Treatment
- Labs
- Risk

IMD

Home
Colorado, Breckenridge #343204 IMD IMD

Metabolic Screen

Urgent Tracked

Assession No.: <input type="text"/>	NBS Test: Medium chain acyl-CoA dehydrogenase deficiency
Date Drawn: 04/02/2013	Sample Number: One
Date Lab Received: 04/03/2013	Result: Abnormal
Date Reported: 04/04/2013	Value: <input type="text"/>
Date Follow-up: <input type="text"/>	Doctor/Provider: NBS Provider
Date Outcome: <input type="text"/>	Outcome:

Notes:

Analyte

Follow-up

Outcome

Record Information

Updated:	4/23/2013 3:32:00 PM
Updated By:	ewright
Created:	4/23/2013 3:32:00 PM
Created By:	ewright

Close
Update
Delete

IMD Option Menu



Tuesday, April 23, 2013

- Main
- Family
- Add New
- Address
- Contact Information
- Birth
- Race
- IDs
- Providers
- Communication
- Notification
- Diagnosis
- Metabolic Screen
- Metabolic Evaluation
- Developmental Test
- Developmental Outcomes
- Outcome Measures
- Specialty Evaluation
- Urgent Emergency Care
- Metabolic Treatment
- Labs
- Risk

IMD

Home
Colorado, Breckenridge #343204 IMD IMD

Metabolic Screen

Analyte

Analyte

	ID	Analyte	Value	CutOffValue	Result	Updated
Select	1100	C8	10.6	0.40	ABN	4/23/2013 3:32:00 PM
Select	1101	C8/C10	5.62	2.00	ABN	4/23/2013 3:33:00 PM

Follow-up

Outcome

Record Information

Updated: 4/23/2013 3:32:00 PM
 Updated By: ewright
 Created: 4/23/2013 3:32:00 PM
 Created By: ewright

IMD Option Menu



Tuesday, April 23, 2013

- Main
- Family
- Add New
- Address
- Contact Information
- Birth
- Race
- IDs
- Providers
- Communication
- Notification
- Diagnosis
- Metabolic Screen
- Metabolic Evaluation
- Developmental Test
- Developmental Outcomes
- Outcome Measures
- Specialty Evaluation
- Urgent Emergency Care
- Metabolic Treatment
- Labs
- Risk

IMD

Home
Colorado, Breckenridge #343204 IMD IMD

Metabolic Screen

Analyte

Follow-up

Follow-Up

	ID	ConfirmTest	Requested	Obtained	Pend	Result	Updated
Select	1381	Plasma acylcarnitine profile	04/04/2013	04/05/2013	No	ABN	4/23/2013 3:34:00 PM

Outcome

Record Information

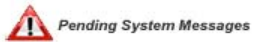
Updated: 4/23/2013 3:32:00 PM

Updated By: ewright

Created: 4/23/2013 3:32:00 PM

Created By: ewright

IMD Option Menu



Tuesday, April 23, 2013

- Main
- Family
- Add New
- Address
- Contact Information
- Birth
- Race
- IDs
- Providers
- Communication
- Notification
- Diagnosis
- Metabolic Screen
- Metabolic Evaluation
- Developmental Test
- Developmental Outcomes
- Outcome Measures
- Specialty Evaluation
- Urgent Emergency Care
- Metabolic Treatment
- Labs
- Risk

Home
Colorado, Breckenridge #343204 IMD IMD

Metabolic Screen

Analyte

Follow-up

Outcome

Positive: False True Unknown

Date Closed:

Dx: 07/07/2013 | Disorders of Fatty Acid Oxidation : Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency : Definite

First Clinic Visit:

Diet/Treatment Initiation:

Notes:

Record Information

Updated: 4/23/2013 3:32:00 PM

Updated By: ewright

Created: 4/23/2013 3:32:00 PM

Created By: ewright

IMD

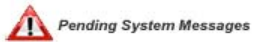
Long-term follow-up (LTFU)

- Datasets developed by the Mountain States Genetics Regional Collaborative's (MSGRC) Metabolic Consortium.
 - Performance indicators
 - Benchmark data to measure, track, and compare
 - Age of diet initiation, freq. of clinic visits, growth parameters, ER visits, diet stats, developmental services, etc.
 - Outcome measures
 - End result of the intervention
 - Mortality, IQ, cardiomyopathy, neurological symptoms, bone findings, final adult growth, etc.

...LTFU

- Only patients with confirmed diagnoses are entered.
 - Clinically diagnosed patients also included to serve as a control population.
- Patients must be consented prior to data entry.
 - Active IRB approved research protocol
- Data is primarily extracted from chart review by research assistant previously funded by the Effective Follow-up in NBS grant.
- Report function utilized for disease-specific queries
 - How many hospitalizations did our patients with MCAD deficiency have in 2012?

IMD Option Menu ▾



Pending System Messages

Tuesday, April 23, 2013

- Main
- Family
- Add New
- Address
- Contact Information
- Birth
- Race
- IDs
- Providers
- Communication
- Notification
- Diagnosis
- Metabolic Screen
- Metabolic Evaluation
- Developmental Test
- Developmental Outcomes
- Outcome Measures
- Specialty Evaluation
- Urgent Emergency Care
- Metabolic Treatment
- Labs
- Risk

IMD

Home
Colorado, Breckenridge #343204 IMD IMD

Close

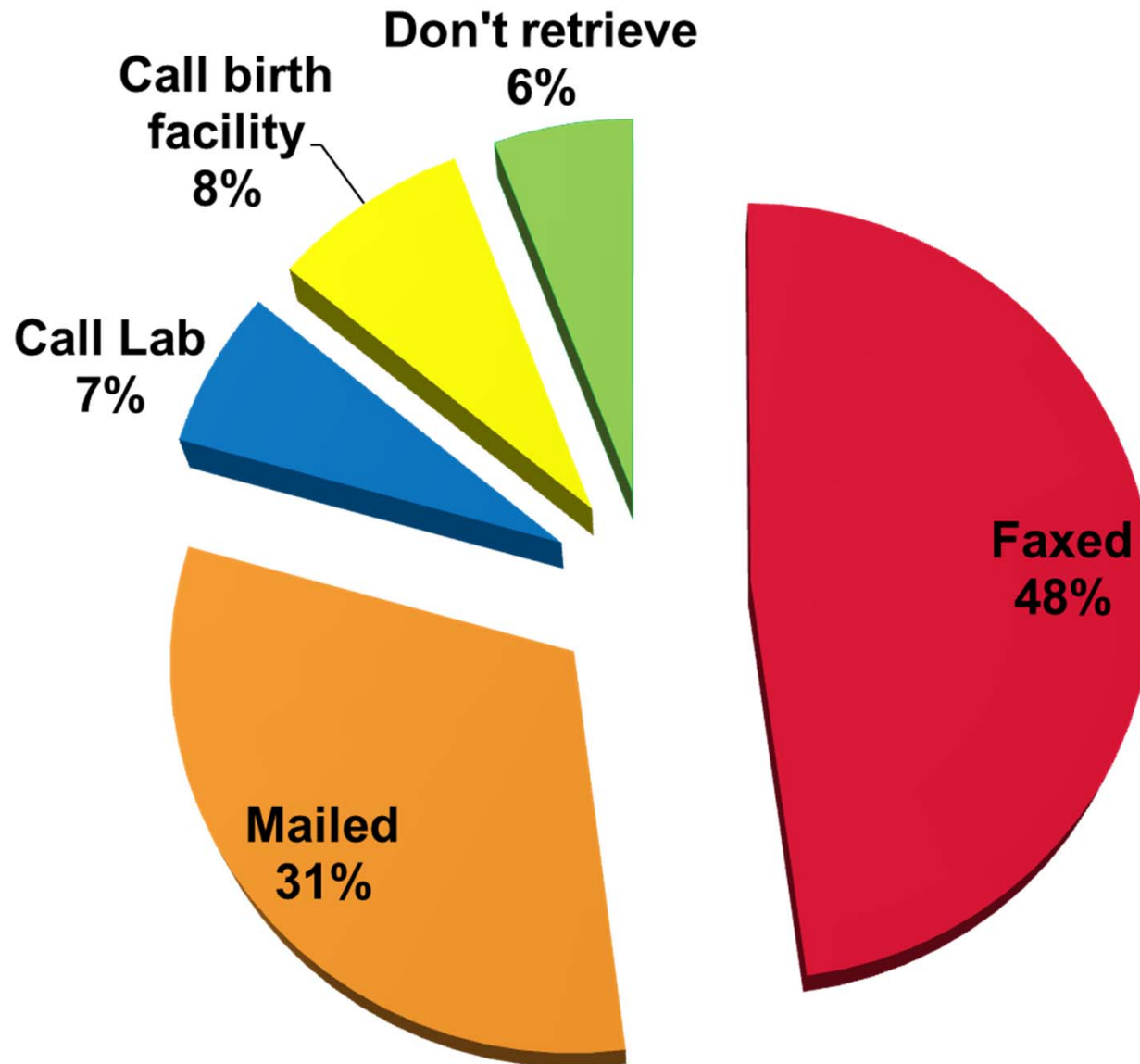
Outcome Measures

- [General Health](#)
- [Hearing/Vision](#)
- [Neurological](#)
- [Cardiac/Vascular](#)
- [Liver/Pancreas](#)
- [Bone/Muscle](#)
- [Hematologic](#)
- [Endocrine](#)
- [Renal](#)
- [Psychiatric](#)
- [Other](#)

Electronic Health Information Exchange (eHIE) survey

- In 2010, as part of our Effective Follow-up in NBS grant, a survey was conducted with providers throughout Colorado and Wyoming.
 - Pediatricians and family practice physicians surveyed
 - 158 responses
- Queried physicians regarding their obtainment of NBS results
 - 77% check for 1st and 2nd NBS results
 - 2% check for only the first
 - 16% check for only the second
 - 5% don't look for results
 - “No news is good news”

Resulting



Additional survey results

- 80.3% of respondents stated they would benefit from eHIE of NBS results
- Functions that would be most valuable to provider in an eHIE:
 - Access to NBS results: 94%
 - Access to immunization records: 89.7%
 - Access to newborn hearing results: 78.1%
- Conclusion:
 - NBS results + immunizations records = happy physicians

Colorado Immunization Information System (CIIS)

- IDS has been linked to CIIS through NEST
- Data acquisition from Specimen Gate being upgraded and refined
 - Includes LOINC and SNOMED codes
- 3 PCP offices will pilot NBS resulting via CIIS this summer with anticipated full-scale launch in the fall.

- 
- Home
 - Patients
 - Search
 - Demographics
 - Local IDs
 - Programs
 - Notes
 - Precautions/Contraindications
 - Events
 - Duplicates
 - Immunizations
 - Treatments
 - Education
 - IZ Quick Add
 - CRA Quick Add
 - Inventory
 - Campaigns
 - NBS
 - Reports/Forms
 - Settings
 - VTrackS Interface
 - Administration

Version 12.9-1
Copyright © 2001-2012
Envision Techn. Partners Inc.

Newborn Screening (Beta Test)

This screen will be used to call the Newborn Screening System to display results for children with documented screenings. Click the "Retrieve NBS Data" button to connect to the NBS system and retrieve data.

View WHITE, JACK (444239) DOB: 09/25/1981 AGE: 31Y 1M 13D

Audiology Section

Completed Date	Initial Screen Yes/No/Unknown	Follow-Up Screen Yes/No/Unknown	Completed Date
Result Left	Passed/Failed	Passed/Failed	Result Left
Result Right	Passed/Failed	Passed/Failed	Result Right

Evaluation Submitted: mm/dd/yyyy Audiologist: First Middle Last Hearing Loss: Yes/No

Laboratory Report 1

Accession #:	99999999999	Form #:	Z 999999 9
Specimen Type:	First/Second	Result Status:	Reprint/Original
<u>Patient Information</u>		<u>Submitted By</u>	
Mother's Name	First Middle Last	Name	First Middle Last
Sex	F/M/T/U	Address	xx street name city, state zip
Weight (g)	99g		
Medical Record	99999999999		
Date Collected	mm/dd/yyyy	Physician	First Middle Last
Date Received	mm/dd/yyyy		
Date Reported	mm/dd/yyyy		
Date Printed	mm/dd/yyyy		
Date Corrected	mm/dd/yyyy		

Disorders	Analyte(s)	Result	Reference Range	Comment

Laboratory Report 2

Accession #:	99999999999	Form #:	Z 999999 9
Specimen Type:	First/Second	Result Status:	Reprint/Original
<u>Patient Information</u>		<u>Submitted By</u>	
Mother's Name	First Middle Last	Name	First Middle Last
Sex	F/M/T/U	Address	xx street name city, state zip
Weight (g)	99g		
Medical Record	99999999999		
Date Collected	mm/dd/yyyy	Physician	First Middle Last
Date Received	mm/dd/yyyy		
Date Reported	mm/dd/yyyy		
Date Printed	mm/dd/yyyy		
Date Corrected	mm/dd/yyyy		

Disorders	Analyte(s)	Result	Reference Range	Comment

Next Steps for IDS (STFU)

- Continued work to successfully link CIIS with IDS
 - Include follow-up recommendations, outcome, etc.
 - Implement an “alert” mechanism
- Harmonization of data fields with NewSTEPs quality indicators
- Facilitate transfer of data to NewSTEPs
- Continued overall quality improvement of NBS program

Next Steps for IDS (LTFU)

- Transfer legacy data to Newborn Screening Translational Research Network's Longitudinal Pediatric Data Resource (LPDR)
- Requires new IRB approved protocol and reconsenting of patients
- Requires data matching /harmonization
- Additional funding requested through MSGRC
- Identify additional funding sources for continued data entry of LTFU into LPDR

Acknowledgements

- *The Mountain States Genetics Regional Collaborative Center (MSGRCC) is supported by cooperative agreement #U22MC10761 with the United States Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau, Genetic Services Branch.*
- *The Effective Follow-up in Newborn Screening grant is funded by cooperative agreement #2581292, ST 63100006 with HRSA, Maternal and Child Health Bureau, Genetic Services Branch.*



Thank you!

- Children's Hospital/University of Colorado team
 - Janet Thomas, MD
- CDPHE IT team
 - Bruce Straw
 - Paul Turtle
 - Chris Wells, PhD
- CDPHE NBS lab
 - Mark Dymerski
 - Dan Wright