
ALLIANCE FOR INNOVATION
ON MATERNAL HEALTH

# Perinatal Mental Health Conditions

## Patient Safety Bundle

**Chelsea Lennox, MPH**

Lead Program Manger

Alliance for Innovation on Maternal Health

# Alliance for Innovation on Maternal Health

- National quality improvement initiative
- Support best practices that **make birth safer**, **improve maternal health outcomes**, and **save lives**
- Supported by a cooperative agreement between HRSA and ACOG

# Alliance for Innovation on Maternal Health

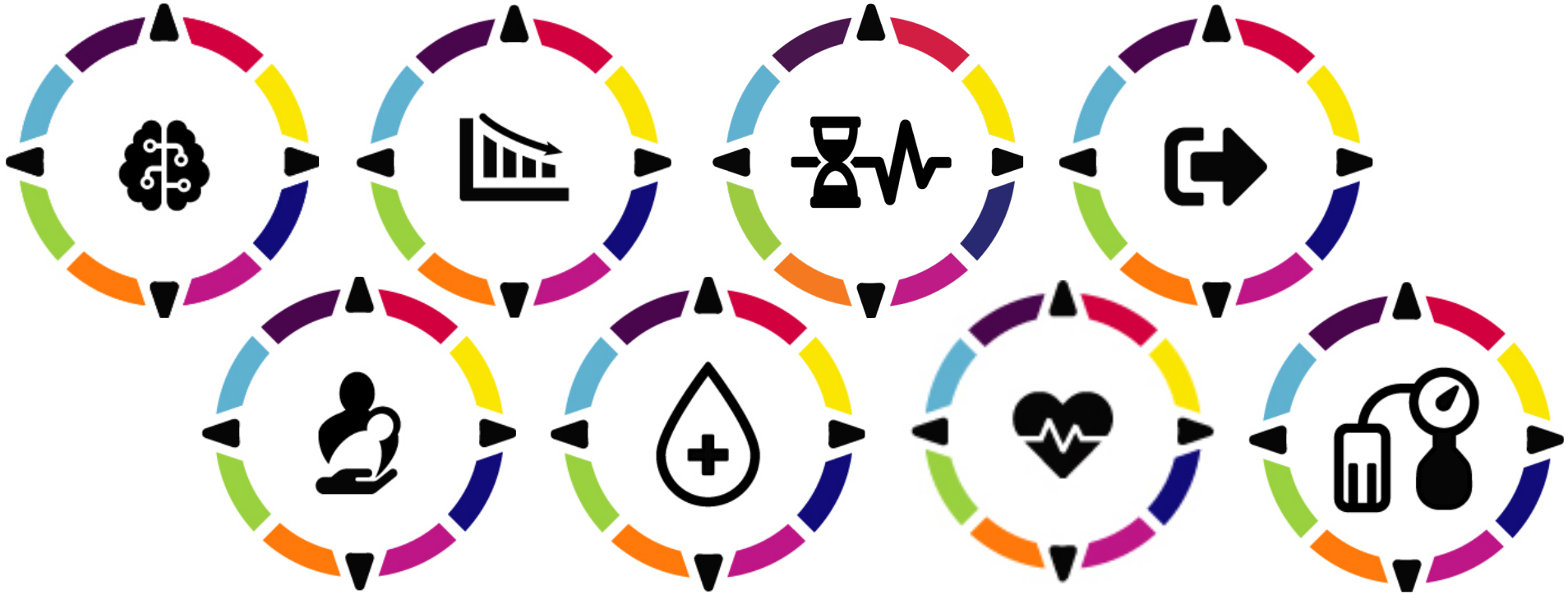
This program is supported by a cooperative agreement with the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number UC4MC28042, Alliance for Innovation on Maternal Health. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

# Alliance for Innovation on Maternal Health

- AIM's primary goal is to **reduce preventable maternal mortality and severe maternal morbidity** in the United States

- AIM provides innovative training and implementation support for AIM patient safety bundles

# Patient Safety Bundles



# Perinatal Mental Health Conditions

# Perinatal Mental Health Conditions

- **A leading cause of maternal mortality**

- Includes depression, anxiety and anxiety-related disorders like post-traumatic stress disorder and obsessive-compulsive disorder, bipolar disorder, and postpartum psychosis

- Can occur **during pregnancy or within the first year postpartum**

# Perinatal Mental Health Conditions

- Perinatal mental health conditions affect upwards of **1 in 5 people**[1]

- Mental health conditions, including suicide and overdose, account for approximately **10% of pregnancy-related deaths**

- MMRC's have determined **100%** of these deaths to be **preventable**[2]

1. Wisner 2013; Fawcett 2019; Masters 2022
2. Davis 2019, Trost 2021

# Bundle Revision

- The Maternal Mental Health Patient Safety Bundle was originally released **over 7 years ago**

- In January 2022, revision to widen the scope of the bundle to:
  - Include additional health conditions
  - Incorporate respectful equitable and supportive care considerations
  - Create metrics and data collection plans to support

# Equity Considerations


- 5R Framework – Respectful, Equitable, and Supportive Care
- All AIM patient safety bundles incorporate aspects of respectful care
- Data collection plans support disaggregating data by race, ethnicity, payor, and other SDOH when possible

# Bundle Revision Workgroup

## Revision Workgroup

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# Bundle Revision External Reviewers

## Representation from...

American College of Obstetricians and Gynecologists
National Healthy Start Association
2020 Mom
American College of Nurse Midwives
Association of Women's Health, Obstetric and Neonatal Nurses
National Association of Nurse Practitioner in Women's Health
Postpartum Support International
Patients with Lived Experience
State Teams/PQC's
And more...

# How to Access the Bundle

- www.saferbirth.org
  - Bundle
  - Implementation Details
  - Resource List
  - IHI Change Package
  - Data Collection Plan

# Thank you

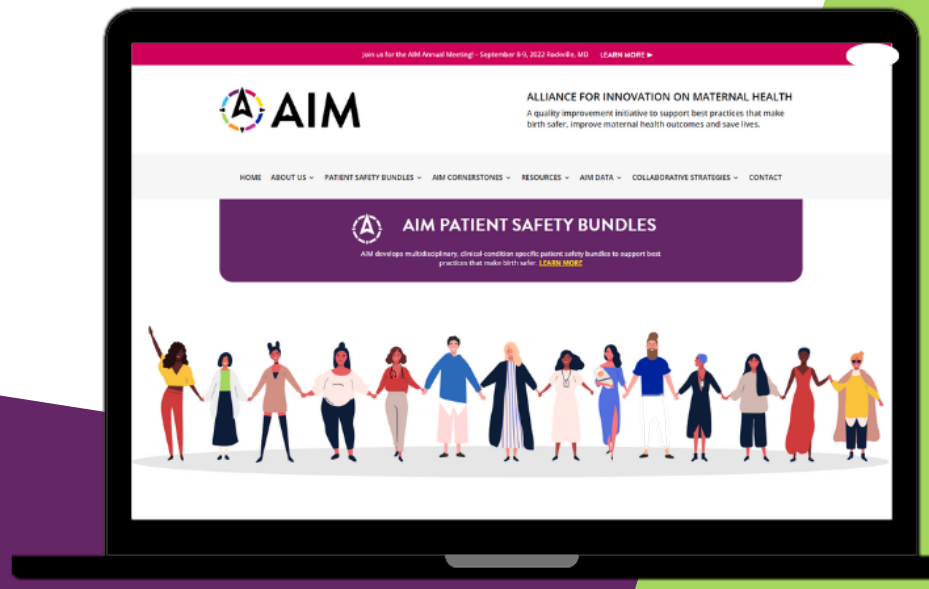
AIM

ALLIANCE FOR INNOVATION ON MATERNAL HEALTH

www.saferbirth.org

www.vimeo.com/aimprogram

aim@acog.org

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# Kentucky Newborn Screening

Lea Mott

MT (ASCP)

**August 10, 2023**

Kentucky Public Health
Prevent. Promote. Protect.

Accredited Health Department • Public Health Accreditation Board •
PHAB
Advancing public health performance

TEAM KENTUCKY®
CABINET FOR HEALTH AND FAMILY SERVICES

# Learning Objectives

- Brief overview of the Newborn Screening (NBS) lab in Kentucky
- Incidence Rates
- Newborn Screen Reports Portal

# Kentucky Department for Public Health

## Mission and Vision in Action

Healthier People,
Healthier Communities.

Our mission is to improve the health and safety of people in Kentucky through prevention, promotion and protection.

**Prevention**

- Diabetes Prevention
- Disease Surveillance
- Environmental Inspections
- HANDS

**Promotion**

- Immunizations
- KEIS
- Mobile Harm Reduction
- Newborn Screening

**Protection**

- Prescription Assistance
- Public Health and Disaster Preparedness
- Smoking Cessation
- WIC

# The Newborn Screening Laboratory in KY

- Location: Centralized Laboratory Facility in Frankfort
- Annual Volume: Kentucky's birth rate is approximately 52,000 babies per year; ~180 specimens/day
- Days Performed: Monday-Saturday and all holidays except Thanksgiving Day, Christmas Day, and New Year's Day

# Recommended Uniform Screening Panel (RUSP)

- RUSP: Disorders recommended by the Secretary of the Department of Health and Human Services
  - 36 Core disorders
  - 26 Secondary disorders
- It is recommended that every newborn be screened for all disorders on the RUSP
- Kentucky Newborn Screening Statute is written to align with the Recommended Uniform Screening Panel (RUSP)

https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp

# How Conditions are Added to the RUSP

- Adding a new condition to the RUSP is a multistep process: First, someone nominates the condition to the RUSP. Any person or group(s) can do this by completing a nomination package.
- The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) meet regularly to discuss proposals from parent advocates, organizations and experts in order to keep newborn screening up to date. In addition, the Secretary of the U.S. Department of Health and Human Services reviews the Committee's recommendations.
- Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.

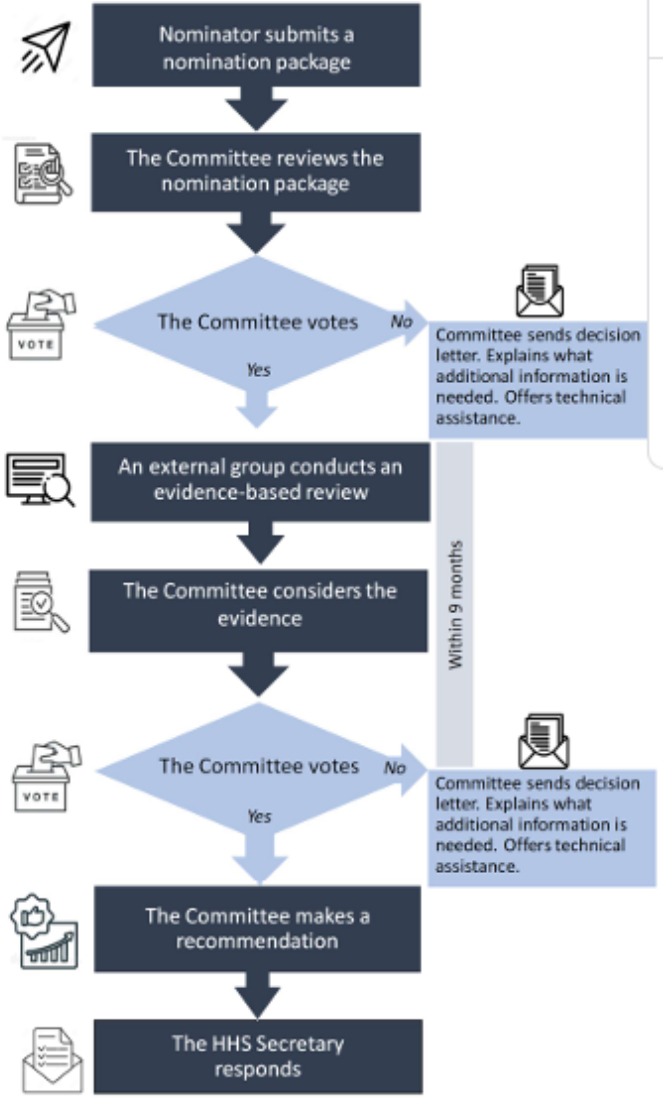
# Steps for Adding a Condition to the RUSP

**Steps for Adding a Condition to the Recommended Uniform Screening Panel (RUSP)**

| Step | Description |
|---|---|
| Nominator submits a nomination package | To start the process, a team of experts and stakeholders complete a nomination package and submit it to the Committee.* |
| Committee reviews the nomination package | The Committee reviews the nomination package. It considers whether the package met the requirements and addressed key questions about the condition, screening process, and treatment. If the nomination package has met the requirements, a Committee member presents a summary at a full Committee meeting. |
| The Committee votes: | The Committee reviews and discusses the nomination further. If the nomination requirements are met, then the Committee will vote on whether or not to move the condition forward for more review. If the full Committee review and discussion finds that the nomination package does not meet requirements, the Committee may choose not to vote and ask the nominators to provide missing information and/or provide nominators with technical assistance on developing the nomination package. |
| *No* | If the Committee votes *no*, the condition does not move forward. The Committee will explain what else is needed, and provide technical assistance to the nominators |
| *Yes* | If the Committee votes *yes*, the condition moves forward for an evidence-based review. |
| The ERG conducts an Evidence-Based Review | In an evidence-based review, an external Evidence-Based Review Group (ERG) gathers detailed data on how screening and treatment for the condition affect newborns, the population, and the public health system. The ERG prepares a final report and presents it to the Committee. |
| The Committee considers the evidence | The Committee reviews the ERG report, then discusses and rates the data on three main points: screening benefits, screening feasibility, and state readiness to begin screening. |
| The Committee votes: | The Committee votes on whether to recommend adding the nominated condition to the RUSP. |
| *No* | If the Committee votes *no*, it does not recommend adding the condition. The Committee will explain about what else is needed, and provide technical assistance to the nominators. |
| *Yes* | If the Committee votes *yes*, it recommends adding the condition to the RUSP by sending a letter to the HHS Secretary. |
| HHS Secretary responds | The HHS Secretary reviews the Committee recommendation and decides whether or not to add the condition to the RUSP. |

**The full name of the Committee involved is the "Advisory Committee on Heritable Disorders in Newborns and Children." The Consumer Guide uses the term "Committee" to refer to this group.*

**Diagram of Steps for Adding a Condition to the RUSP**



# NBS Panel in Kentucky

- **Fatty Acid Oxidation Disorders:**
  - **Carnitine Uptake Defect (CUD)**
  - **Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCADD)**
  - **Long-chain Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHADD)**
  - **Trifunctional Protein Deficiency (TFP)**
  - **Very Long-chain Acyl-CoA Dehydrogenase Deficiency (VLCADD)**
  - Short-chain Acyl-CoA Dehydrogenase Deficiency (SCADD)
  - Carnitine Acylcarnitine Translocase Deficiency (CACT)
  - Carnitine Palmitoyl Transferase 1 Deficiency (CPT-1)
  - Carnitine Palmitoyl Transferase 2 Deficiency (CPT-2)
  - Ethylmalonic Encephalopathy (EE)
  - Glutaric Acidemia Type 2 (GA-2)
  - 2,4 Dienoyl-CoA Reductase Deficiency (DE RED)

- **Organic Acid Disorders:**
  - **3-Methlycrotonyl-CoA Carboxylase Deficiency (3MCC)**
  - **Glutaric Acidemia Type 1 (GA-1)**
  - **Beta-kethothiolase Deficiency (BKT)**
  - **Hydroxymethylglutaric Aciduria (HMG)**
  - **Isovaleric Acidemia (IVA)**
  - **Multiple Carboxylase Deficiency (MCD)**
  - **Methylmalonic Acidemia (MMA Cbl A form and MMA Cbl B form)**
  - **Methylmalonyl-CoA Mutase Deficiency (MUT)**
  - **Propionic Acidemia (PA)**
  - 2-Methyl-3-Hydroxybutyric Aciduria (2M3HBA)
  - 2-Methylbutyryl-CoA Dehydrogenase Deficiency (2MBDH)
  - 3-Methylglutaconic Aciduria (3MGA)
  - Methylmalonic Acidemia (MMA Cbl C form and MMA Cbl D form)
  - Malonic Acidemia (MAL)
  - Isobutyryl-CoA Dehydrogenase Deficiency (IBG)

- **Amino Acid Disorders:**
  - **Argininosuccinic Aciduria (ASA)**
  - **Citrullinemia (CIT-1)**
  - **Homocystinuria (HCY)**
  - **Maple Syrup Urine Disease (MSUD)**
  - **Phenylketonuria (PKU)**
  - **Tyrosinemia Type 1 (TYR-1)**
  - Citrullinemia Type 2 (CIT-2)
  - Hypermethioninemia (MET)
  - Hyperphenylalaninemia (H-PHE)Tyrosinemia Type 2 (TYR-2)
  - Tyrosinemia Type 3 (TYR-3)
  - Arginase Deficiency (ARG)
  - Non-Ketotic Hyperglycinemia (NKHG)

- **Endocrine Disorders:**
  - **Congenital Adrenal Hyperplasia (CAH)**
  - **Congenital Hypothyroidism (TSH and T4)**

- **Hemoglobin Disorders:**
  - **Hb S/Beta-thalassemia (HbS/Th)**
  - **Hb S/C Disease (Hb S/C)**
  - **Sickle Cell Anemia (Hb S/S)**
  - Various Hemoglobinopathies (includes Hb E)

- **Lysosomal and Peroxisomal Disorders:**
  - **Mucopolysaccharidosis (MPS-1, Hurler's Disease)**
  - **Pompe**
  - Krabbe
  - **X-linked adrenoleukodystrophy (X-ALD)**

- **Other Disorders:**
  - **Cystic Fibrosis (CF)**
  - **Galactosemia (GAL)**
  - **Biotinidase Deficiency (BIOT)**
  - **Severe Combined Immunodeficiency (SCID)**
  - **Spinal Muscular Atrophy (SMA)**

- **Point of Care Testing:**
  - **Critical Congenital Heart Defects**
  - **Hearing**

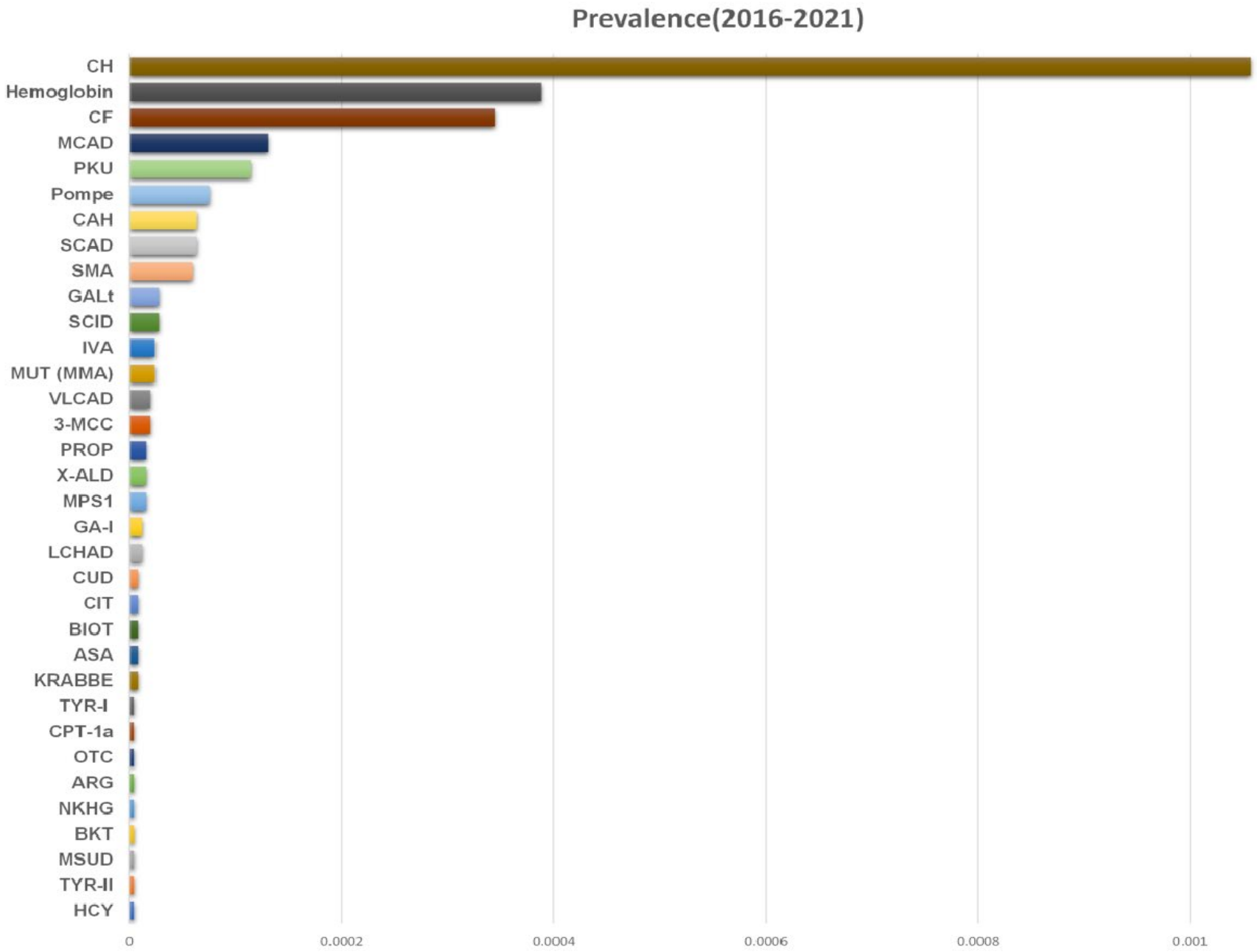
Core Conditions in Bold

55 disorders in total

| Conditions | 2016 True positive | 2017 true positive | 2018 true positive | 2019 true positive | 2020 true positive | 2021 true positive | Prevalence rate | Incidence Rate |
|---|---|---|---|---|---|---|---|---|
| 3-MCC | 1 | 2 | 0 | 2 | 5/252,508 | 1/50,502 | | |
| ARG | 1 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | | |
| ASA | 0 | 1 | 1 | 0 | 2/252,508 | 1/126,254 | | |
| BIOT | 0 | 0 | 1 | 0 | 2/252,508 | 1/126,254 | | |
| BKT | 1 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | | |
| CAH | 4 | 1 | 4 | 1 | 16/252,508 | 1/15,782 | | |
| Cbl A,B | 0 | 0 | 0 | 0 | 0 | | | |
| CF | 12 | 27 | 18 | 15 | 87/252,508 | 1/2,902 | | |
| CH | 45 | 54 | 66 | 53 | 258/252,508 | 1/979 | | |
| CIT | 0 | 0 | 0 | 1 | 2/252,508 | 1/126,254 | | |
| CPT-1a | 0 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | | |
| CPT-II | 0 | 0 | 0 | 0 | 0 | | | |
| CUD | 0 | 0 | 0 | 2 | 0 | 2/252,508 | 1/126.254 | |
| EE | 0 | 0 | 0 | 0 | 0 | | | |
| GA-I | 1 | 0 | 2 | 0 | 0 | 3/252,508 | 1/84,169 | |
| GA-II | 0 | 0 | 0 | 0 | 0 | | | |
| GALt | 2 | 2 | 2 | 0 | 1 | 7/252,508 | 1/36,073 | |
| Hemoglobin | 15 | 31 | 12 | 25 | 16 | 99/252,508 | 1/2,577 | |
| HCY | 1 | 0 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | |
| IVA | 0 | 1 | 1 | 3 | 1 | 6/252,508 | 1/42,085 | |
| KRABBE | 1 | 0 | 0 | 0 | 0 | 1 | 2/298,084 | 1/126,254 |
| LCHAD | 0 | 0 | 0 | 1 | 1 | 3/252,508 | 1/84,176 | |
| MCAD | 3 | 10 | 8 | 4 | 8 | 33/252,508 | 1/7,652 | |
| MCD | 0 | 0 | 0 | 0 | 0 | | | |
| MPS1 | 1 | 1 | 1 | 1 | 1 | 0 | 4/298,084 | 1/74,521 |
| MSUD | 0 | 0 | 1 | 0 | 0 | 1/252,508 | 1/252,508 | |
| MUT (MMA) | 2 | 1 | 2 | 1 | 0 | 6/252,508 | 1/42,085 | |
| NKHG | 0 | 1 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | |
| OTC | 0 | 1 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | |
| PHE | 0 | 0 | 0 | 0 | 0 | | | |
| PKU | 4 | 9 | 3 | 2 | 11 | 29/252,508 | 1/8,707 | |
| Pompe | 3 | 6 | 1 | 7 | 2 | 20/298,084 | 1/14,904 | |
| PROP | 1 | 2 | 0 | 1 | 0 | 4/252,508 | 1/63,127 | |
| SCAD | 6 | 2 | 5 | 1 | 2 | 16/252,508 | 1/15,782 | |
| SCHAD | 0 | 0 | 0 | 0 | 0 | | | |
| SCID | 1 | 0 | 1 | 2 | 3 | 7/252,508 | 1/36,073 | |
| SMA | N/A | N/A | 4 | 4 | 7 | 15/114,154 | 1/7,610 | |
| TYR-I | 0 | 1 | 0 | 0 | 0 | 1/252,508 | 1/252,508 | |
| TYR-II | 0 | 0 | 0 | 1 | 0 | 1/252,508 | 1/252,508 | |
| VLCAD | 1 | 1 | 2 | 0 | 1 | 5/252,508 | 1/50,502 | |
| X-ALD | N/A | 1 | 2 | 0 | 1 | 4/174,568 | 1/43,642 | |
| Total True Positives | | | | 137 | 125 | 121 | | |
| Average True Positives out of annual specimens | | | | 1/400 | 1/400 | 1/400 | | |

2017: 52, 012 initial specimens
2018: 51,400 initial specimens
2019: 50, 520 initial specimens
2020: 49,056 initial specimens
2021: 49,520 initial specimens

initial specimens


Prevalence(2016-2021)
CH
Hemoglobin
CF
MCAD
PKU
Pompe
CAH
SCAD
SMA
GALt
SCID
IVA
MUT (MMA)
VLCAD
3-MCC
PROP
X-ALD
MPS1
GA-I
LCHAD
CUD
CIT
BIOT
ASA
KRABBE
TYR-I
CPT-1a
OTC
ARG
NKHG
BKT
MSUD
TYR-II
HCY
0
0.0002
0.0004
0.0006
0.0008
0.001

# Division of Laboratory Services

## *Kentucky Hospitals, Health Departments, and Birthing Facilities*

Kentucky Public Health
Prevent. Promote. Protect.

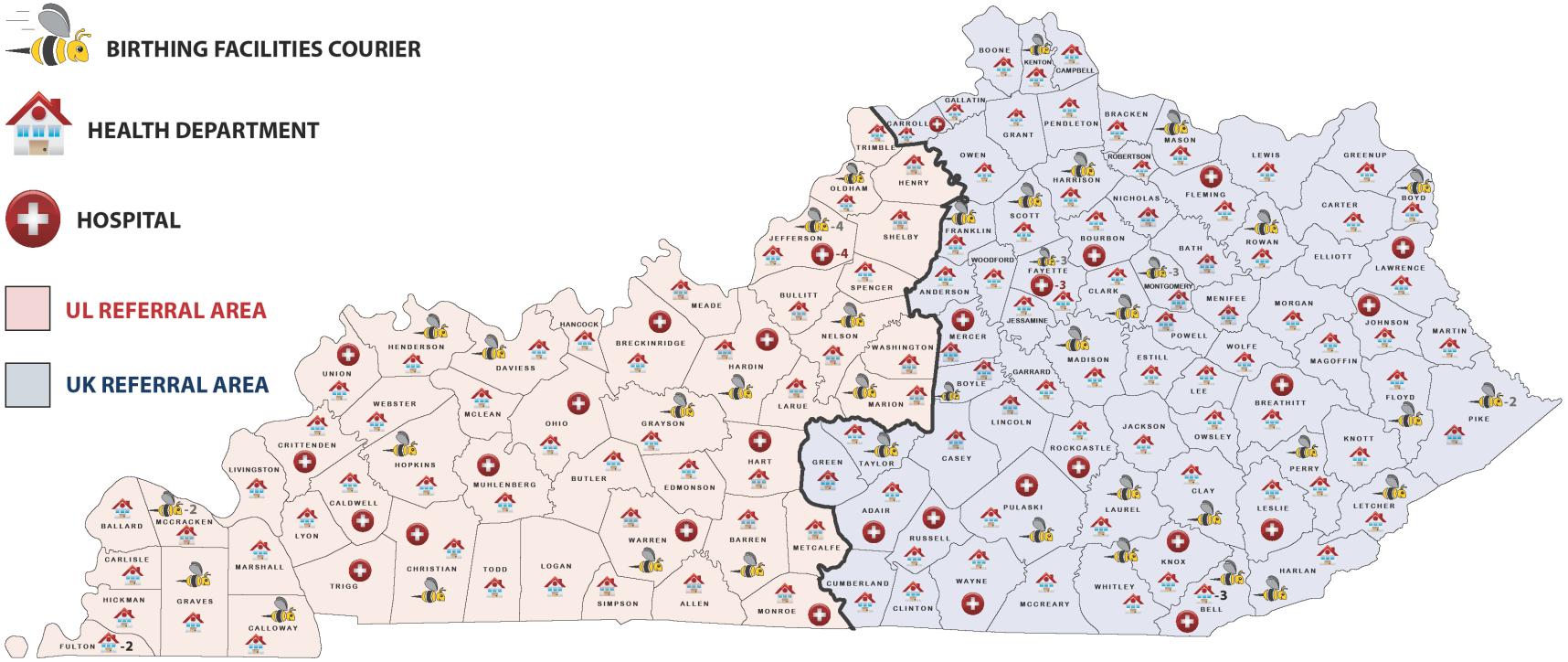
BIRTHING FACILITIES COURIER

HEALTH DEPARTMENT

HOSPITAL

UL REFERRAL AREA

UK REFERRAL AREA




### BIRTHING FACILITIES - CITY - COUNTY

| | | | | | |
|---|---|---|---|---|---|
| Baptist Health Corbin | Corbin | Whitley -Knox | St. Claire Regional Medical Center | Morehead | Rowan |
| Baptist Health LaGrange | LaGrange | Oldham | St Elizabeth Health Care | Edgewood | Kenton |
| Baptist Health Lexington | Lexington | Fayette | Women's Hospital at St Joseph East | Lexington | Fayette |
| Baptist Health Louisville | Louisville | Jefferson | St Joseph London | London | Laurel |
| Baptist Health Madisonville | Madisonville | Hopkins | St Joseph Mount Sterling | Mount Sterling | Montgomery |
| Baptist Health Paducah | Paducah | McCracken | St Joseph Mount Sterling | Mount Sterling | Montgomery |
| Baptist Health Richmond | Richmond | Madison | St Joseph Mount Sterling | Mount Sterling | Montgomery |
| Clark Regional Medical Center | Winchester | Clark | Taylor Regional Hospital | Campbellsville | Taylor |
| Ephraim McDowell Fort Logan | Stanford | Lincoln | The Medical Center at Bowling Green | Bowling Green | Warren |
| Ephraim McDowell Regional | Danville | Boyle | TJ Sampson Community | Glasgow | Barren |
| Flaget Memorial | Bardstown | Nelson | Twin Lakes Regional Medical Center | Leitchfield | Grayson |
| Frankfort Regional Medical Center | Frankfort | Franklin | UK Hospital | Lexington | Fayette |
| Georgetown Community | Georgetown | Scott | UofL Hospital | Louisville | Jefferson |
| Baptist Health Hardin | Elizabethtown | Hardin | Whitesburg ARH | Whitesburg | Letcher |
| Harlan ARH Hospital | Harlan | Harlan | Williamson ARH/ Tug Valley | South Williamson | Pike |
| Harrison Memorial Hospital | Cynthiana | Harrison | | | |
| Hazard ARH Regional | Hazard | Perry | | | |
| Highlands ARH Regional | Prestonsburg | Floyd | | | |
| Jackson Purchase Medical Center | Mayfield | Graves | | | |
| Jennie Stuart Medical Center | Hopkinsville | Christian | | | |
| King's Daughter Medical Center | Ashland | Boyd | | | |
| Lake Cumberland Regional | Somerset | Pulaski | | | |
| Lourdes | Paducah | McCracken | | | |
| Advent Health Manchester | Manchester | Clay | | | |
| Meadowview Regional | Maysville | Mason | | | |
| Deaconess Henderson | Henderson | Henderson | | | |
| Middlesboro ARH Hospital | Middlesboro | Bell | | | |
| Murray Calloway County | Murray | Calloway | | | |
| Norton Hospital | Louisville | Jefferson | | | |
| Norton Childrens Hospital | Louisville | Jefferson | | | |
| Norton Women and Childrens Hospital | Louisville | Jefferson | | | |
| Owensboro Medical Health System | Owensboro | Daviess | | | |
| Pikeville Medical Center | Pikeville | Pike | | | |
| Spring View Hospital | Lebanon | Marion | | | |

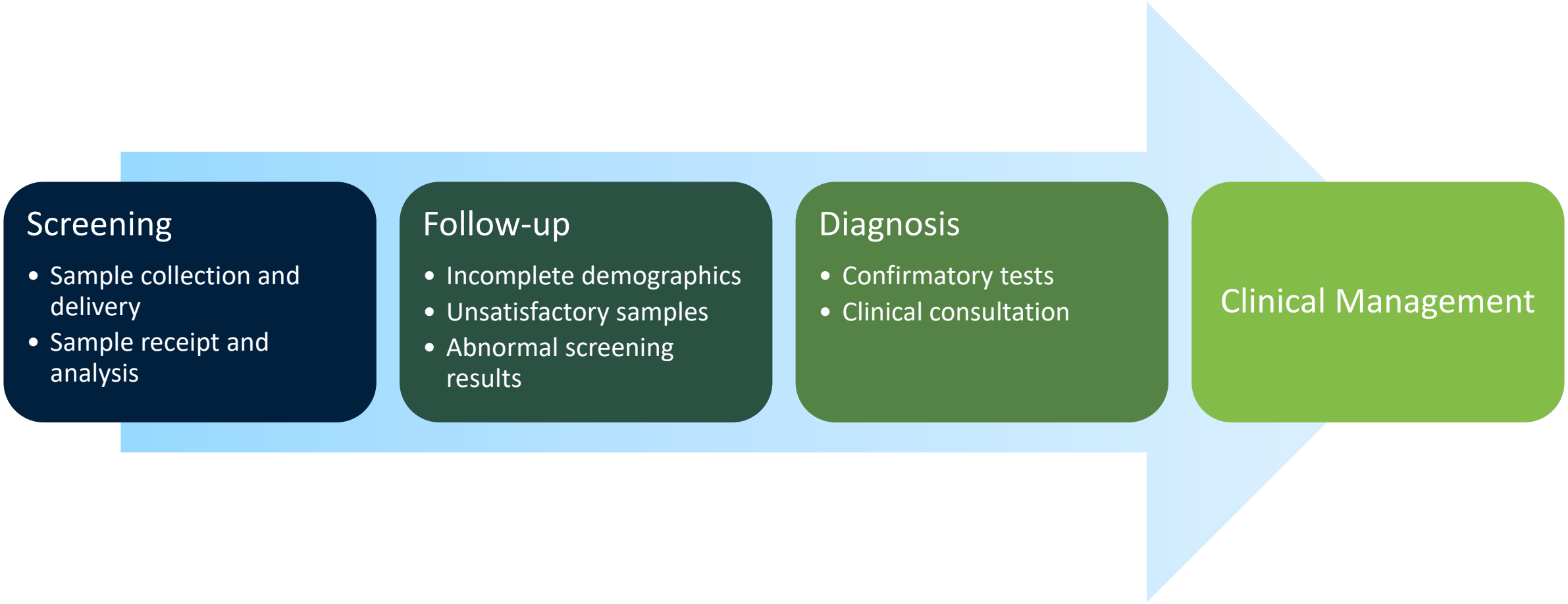
### HEALTH DEPARTMENT - CITY - COUNTY

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Adair County | Columbia | Adair | Estill | Irvine | Estill | Lewis | Vanceburg | Lewis | Powell |
| Allen County | Scottsville | Allen | Fleming | Flemingsburg | Fleming | Lexington Fayette | Lexington | Fayette | Pulaski |
| Anderson County | Lawrenceburg | Anderson | Floyd | Prestonsburg | Floyd | Lincoln | Stanford | Lincoln | Robertson |
| Ashland-Boyd | Ashland | Ashland-Boyd | Franklin | Frankfort | Franklin | Livingston | Smithland | Livingston | Rockcastle |
| Ballard | LaCenter | Ballard | Fulton | Hickman | Fulton | Logan | Russellville | Logan | Rowan |
| Barren | Glasgow | Barren | Fulton East | Fulton | Fulton | Louisville Metro Health | Louisville | Jefferson | Russel |
| Bath | Owingsville | Bath | Gallatin | Warsaw | Gallatin | Lyon | Eddyville | Lyon | Scott |
| Bell | Pineville | Bell | Garrard | Lancaster | Garrard | Magoffin | Salyersville | Magoffin | Shelby |
| Bell - Middlesboro | Middlesboro | Bell | Grant | Williamstown | Grant | Madison | Richmond | Madison | Simpson |
| Bourbon | Paris | Bourbon | Graves | Mayfield | Graves | Marion | Lebanon | Marion | Spencer |
| Boyle | Danville | Boyle | Grayson | Leitchfield | Grayson | Marshall | Benton | Marshall | Warren |
| Boone | Florence | Boone | Green | Greensburg | Green | Martin | Inez | Martin | Whitley |
| Bracken | Brooksville | Bracken | Greenup | Greenup | Greenup | Mason | Maysville | Mason | Woodford |
| Breathitt | Jackson | Breathitt | Hancock | Hawesville | Hancock | McCreary | Whitley City | McCreary | Taylor |
| Breckinridge | Hardinsburg | Breckinridge | Hardin | Elizabethtown | Hardin | McLean | Calhoun | McLean | Todd |
| Bullitt | Shepardsville | Bullitt | Harlan | Harlan | Harlan | Meade | Brandenburg | Meade | Trimble |
| Butler | Morgantown | Butler | Harrison | Cynthiana | Harrison | Menifee | Frenchburg | Menifee | Union |
| Caldwell | Princeton | Caldwell | Hart | Munfordville | Hart | Mercer | Harrodsburg | Mercer | Washington |
| Calloway | Murray | Calloway | Henderson | Henderson | Henderson | Metcalfe | Edmonton | Metcalfe | Wayne |
| Campbell | Newport | Campbell | Henry | New Castle | Henry | Monroe | Tompkinsville | Monroe | Webster |
| Carlisle | Bardwell | Carlisle | Hickman | Clinton | Hickman | Montgomery | Mt. Sterling | Montgomery | Wolfe |
| Carroll | Carrollton | Carroll | Hopkins | Madisonville | Hopkins | Morgan | West Liberty | Morgan | |
| Carter | Grayson | Carter | Jackson | McKee | Jackson | Muhlenburg | Central City | Muhlenburg | |
| Casey | Liberty | Casey | Jessamine | Nicholasville | Jessamine | Nelson | Bardstown | Nelson | |
| Christian | Hopkinsville | Christian | Johnson | Paintsville | Johnson | Nicholas | Carlisle | Nicholas | |
| Clark | Winchester | Clark | Kenton | Covington | Kenton | Ohio | Hartford | Ohio | |
| Clay | Manchester | Clay | Knott | Hindman | Knott | Oldham | LaGrange | Oldham | |
| Clinton | Albany | Clinton | Knox | Barbourville | Knox | Owen | Owenton | Owen | |
| Crittenden | Marion | Crittenden | Laurel | London | Laurel | Owsley | Booneville | Owsley | |
| Cumberland | Burkesville | Cumberland | Larue | Hodgenville | Larue | Paducah McCracken | Paducah | McCracken | |
| Cumberland Valley Environ | Middlesboro | Bell | Lawerence | Louisa | Lawrence | Pendleton | Falmouth | Pendleton | |
| Daviess | Owensboro | Daviess | Lee | Beattyville | Lee | Pennyrile Environmental | Eddyville | Lyon | |
| Edmonson | Brownsville | Edmonson | Leslie | Hyden | Leslie | Perry | Hazard | Perry | |
| Elliott | Sandy Hook | Elliott | Letcher | Whitesburg | Letcher | Pike | Pikeville | Pike | |

### HOSPITAL - CITY - COUNTY

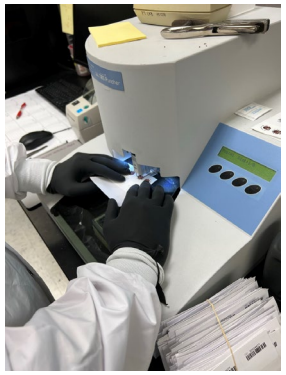
| | | | | | |
|---|---|---|---|---|---|
| Barbourville ARH | Bourbourville | Knox | Lewis | Lexington Fayette | Vanceburg |
| Blanchfield Community Hospital | Fort Campbell | Christian | Lexington | Fayette | Lewis |
| Bourbon Community Hospital | Paris | Bourbon | Stanford | Lincoln | Lincoln |
| Breckinridge Memorial Hospital | Hardinsburg | Breckinridge | Smithland | Livingston | Livingston |
| Caldwell Memorial Hospital | Princeton | Caldwell | Russellville | Logan | Logan |
| Carroll County Hospital | Carrollton | Carroll | Louisville | Jefferson | Louisville |
| Crittenden Health System | Marion | Crittenden | Eddyville | Lyon | Eddyville |
| Cumberland Medical Laboratory | Somerset | Pulaski | Salyersville | Magoffin | Salyersville |
| Fleming County Hospital | Flemingsburg | Fleming | Richmond | Madison | Richmond |
| Greenview Regional Hospital | Bowling Green | Warren | Marion | Marion | Marion |
| Ireland Army Hospital | Fort Knox | Hardin | Marshall | Marshall | Marshall |
| James B Haggin | Harrodsburg | Mercer | Martin | Martin | Martin |
| Jewish Hospital | Louisville | Jefferson | Mason | Mason | Mason |
| Kindred Hospital | Louisville | Jefferson | McCreary | McCreary | McCreary |
| KY River Medical Center | Jackson | Breathitt | McLean | McLean | McLean |
| Mary Breckinridge Hospital | Hyden | Leslie | Meade | Meade | Meade |
| Methodist Hospital Union | Morganfield | Union | Menifee | Menifee | Menifee |
| Monroe Co. Medical Center | Tompkinsville | Monroe | Mercer | Mercer | Mercer |
| Ohio County Hospital | Hartford | Ohio | Metcalfe | Metcalfe | Metcalfe |
| Owensboro Medical Health System Muhlenburg | Greenville | Muhlenburg | Monroe | Monroe | Monroe |
| Paul B Hall Regional Medical Center | Paintsville | Johnson | Montgomery | Montgomery | Montgomery |
| Pineville Medical Center | Pineville | Bell | Morgan | Morgan | Morgan |
| Rockcastle Hospital | Mt. Vernon | Rockcastle | Muhlenburg | Muhlenburg | Muhlenburg |
| Roederer Correctional | LaGrange | Oldham | Nelson | Nelson | Nelson |
| Russell County Hospital | Russell Springs | Russell | Nicholas | Nicholas | Nicholas |
| Samaritan | Lexington | Fayette | Ohio | Ohio | Ohio |
| St. Joseph Main | Lexington | Fayette | Oldham | Oldham | Oldham |
| St. Mary and Elizabeth | Louisville | Jefferson | Owen | Owen | Owen |
| The Medical Center at Caverna | Horse Cave | Hart | Owsley | Owsley | Owsley |
| TJ Samson Columbia | Columbia | Adair | Paducah McCracken | Paducah | McCracken |
| Three Rivers Medical Center | Louisa | Lawrence | Pendleton | Falmouth | Pendleton |
| Trigg County Hospital | Cadiz | Trigg | Pennyrile Environmental | Eddyville | Lyon |
| VA Medical Center | Louisville | Jefferson | Perry | Hazard | Perry |
| Wayne County Hospital | Monticello | Wayne | Pike | Pikeville | Pike |

# NBS Program in KY

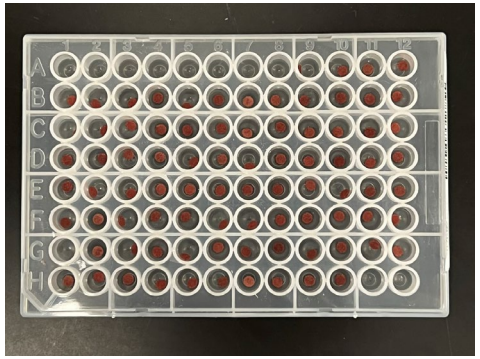


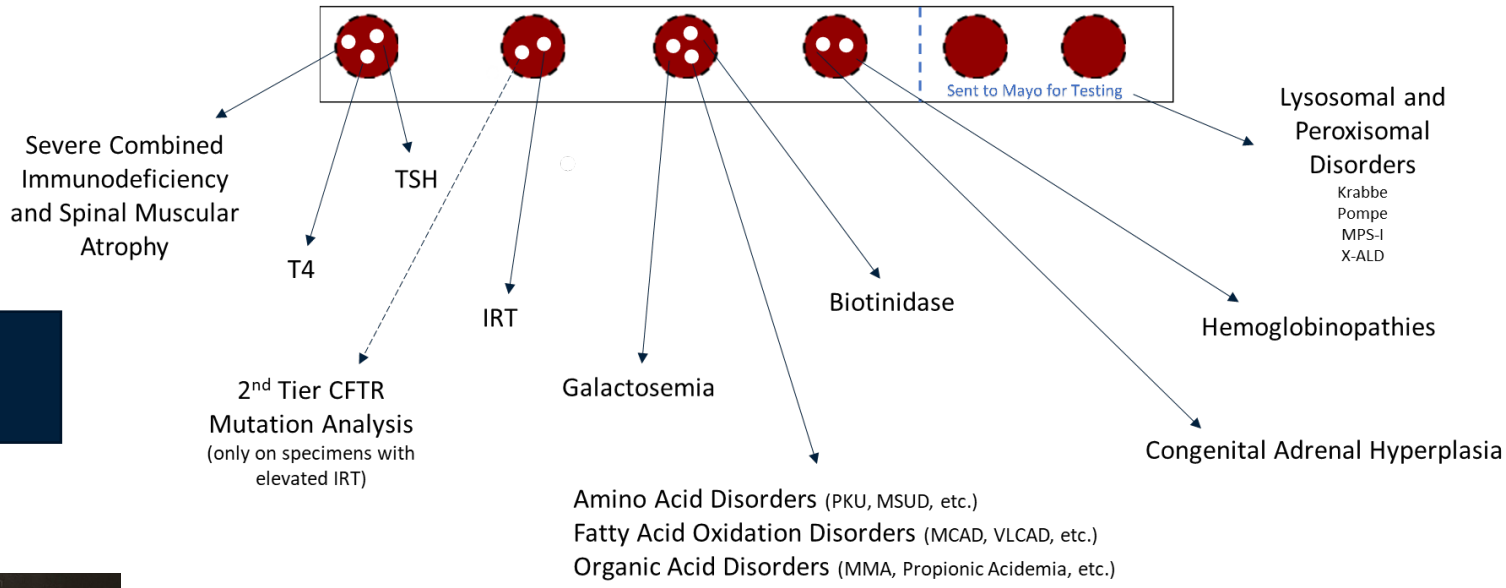
# NBS at KY DLS: Workflow

Specimen Receipt:
Within 24-48hrs of age



Specimen Processing






For approximately 10% of specimens, additional punches are necessary to retest abnormal results.

# NBS in KY: Challenges from Lab Perspective

- National recommendations call for all critical results to be reported within 5 days and all results to be reported within 7 days
- Data from our lab:
  - 6% of specimens are delayed in transit
  - 25% of specimens are collected >30hrs  (Must be 24-48hrs to meet recommendation and we prefer collection closer to 24 hours)
  - Looking at June-December 2022 we had 102 critical specimens and 24 specimens were  >5 days due to collection or transit

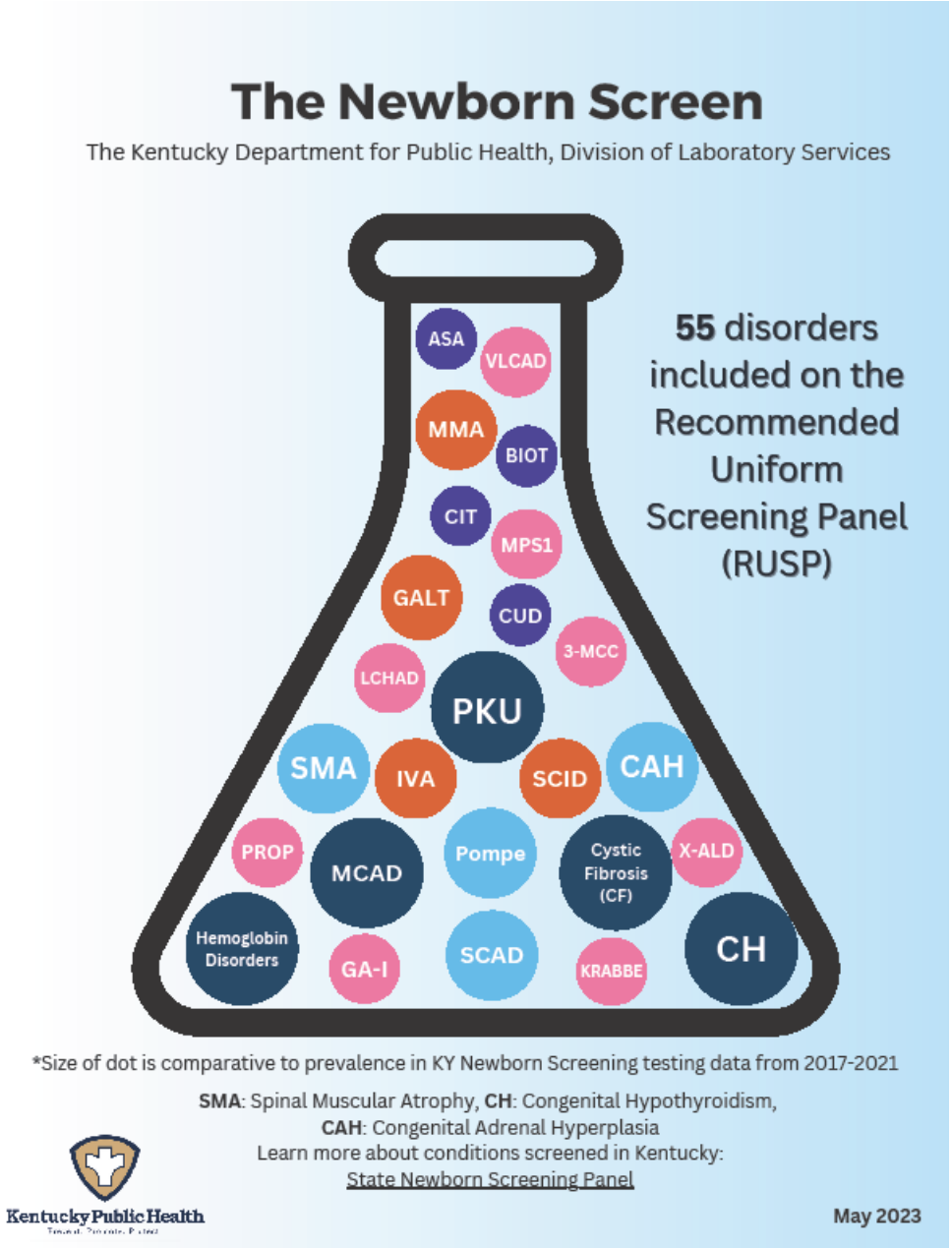
<u>Good quality NBS requires teamwork !</u>


## Help us educate new parents:

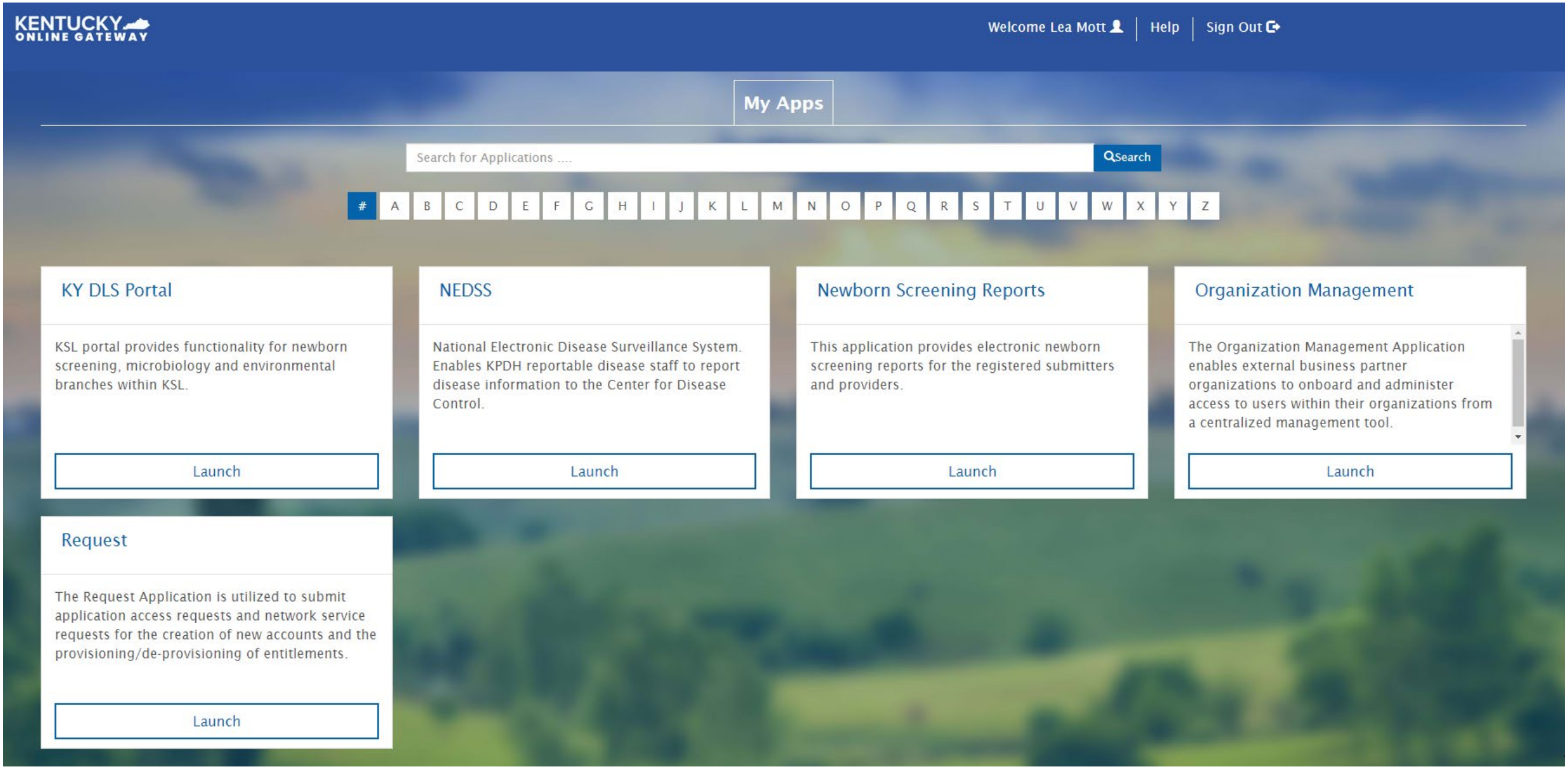
- Encourage them to have a pediatrician chosen prior to delivery
- Remind them to check that the pediatrician is accepting new patients
- Tell them to make sure the pediatrician takes their insurance

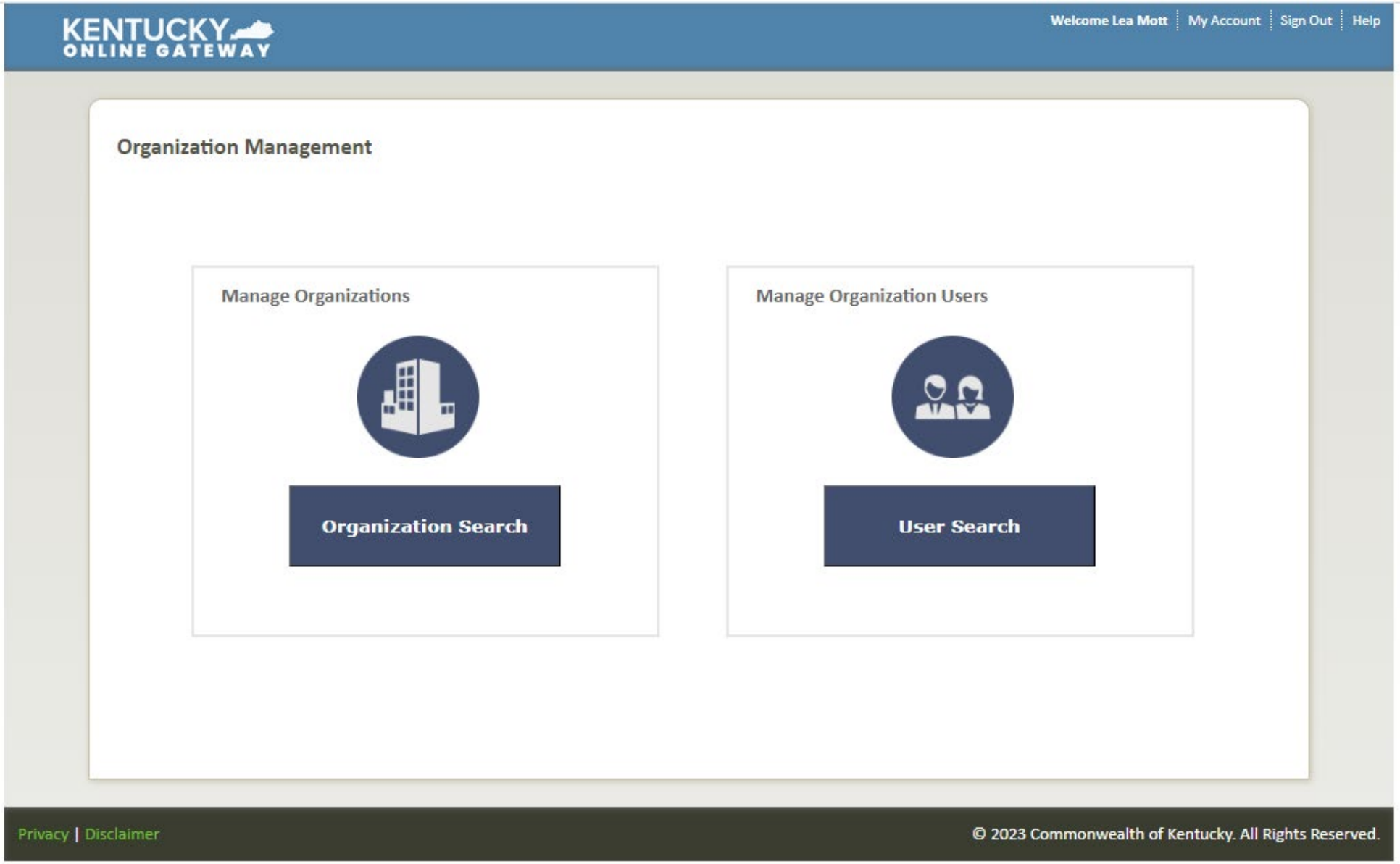
# Newborn screening is more than just PKU

- Help us change the culture of referring to the newborn screen as “the PKU”
- Using one disorder as a shortcut for a panel that includes 54 other disorders leads to confusion



# Newborn Screen Reports Portal


KENTUCKY ONLINE GATEWAY
Welcome Lea Mott
Help
Sign Out
My Apps
Search for Applications ....
Search
# A B C D E F G H I J K L M N O P Q R S T U V W X Y Z
KY DLS Portal
KSL portal provides functionality for newborn screening, microbiology and environmental branches within KSL.
Launch
NEDSS
National Electronic Disease Surveillance System. Enables KPDH reportable disease staff to report disease information to the Center for Disease Control.
Launch
Newborn Screening Reports
This application provides electronic newborn screening reports for the registered submitters and providers.
Launch
Organization Management
The Organization Management Application enables external business partner organizations to onboard and administer access to users within their organizations from a centralized management tool.
Launch
Request
The Request Application is utilized to submit application access requests and network service requests for the creation of new accounts and the provisioning/de-provisioning of entitlements.
Launch


KENTUCKY
ONLINE GATEWAY
Welcome Lea Mott
My Account
Sign Out
Help
Organization Management
Manage Organizations
Organization Search
Manage Organization Users
User Search
Privacy | Disclaimer
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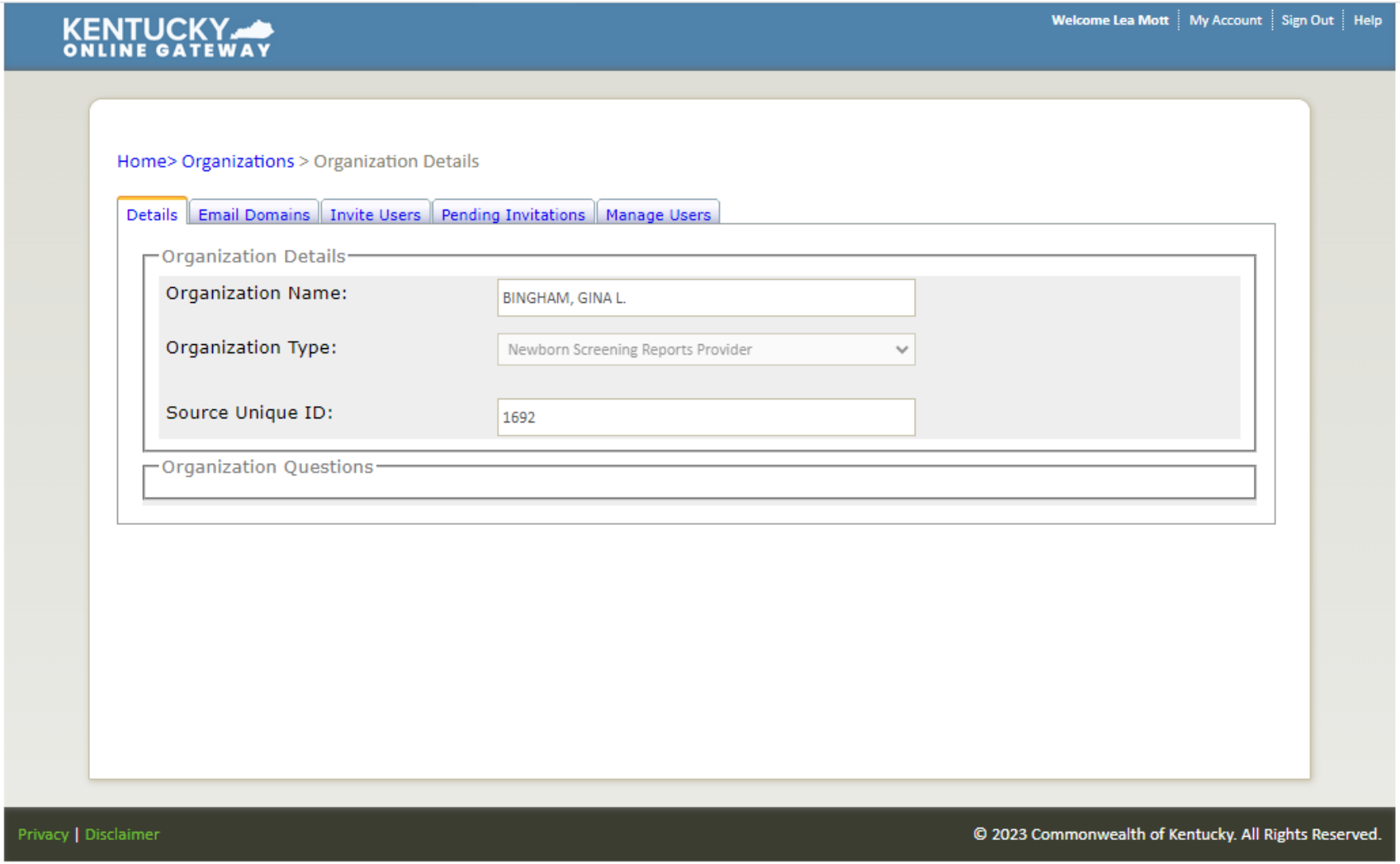
Org Name | Search Type: Starts With | Search

Org Type

| Organization Name | Organization Type Name | |
|---|---|---|
| AGAN, MELISSA D. | Newborn Screening Reports Provider | Manage |
| AHMED, SYED Z. | Newborn Screening Reports Provider | Manage |
| AKAFUAH, RHODA A. | Newborn Screening Reports Provider | Manage |
| AKERS, DAVID BRADLEY | Newborn Screening Reports Provider | Manage |
| ALBERTSON, B. BRADLEY | Newborn Screening Reports Provider | Manage |
| ALEXANDRIA PRIMARY CARE | Newborn Screening Reports Provider | Manage |
| ALISHA RISEN | Newborn Screening Reports Provider | Manage |
| Alison Reid | Newborn Screening Reports Submitter | Manage |
| ALLEN, AMBER | Newborn Screening Reports Provider | Manage |
| ALLGEIER, MAURICE K. | Newborn Screening Reports Provider | Manage |
| ALNAHHAS, MOHAMAD H. | Newborn Screening Reports Provider | Manage |
| ANSERT, DOUGLAS | Newborn Screening Reports Provider | Manage |
| ARH REGIONAL MEDICAL CENTER HAZARD | Newborn Screening Reports Submitter | Manage |
| BAILEY, DEBRA R. | Newborn Screening Reports Provider | Manage |
| BAPTIST HEALTH CORBIN | Newborn Screening Reports Submitter | Manage |
| BAPTIST HEALTH DEACONESS PEDIATRICS | Newborn Screening Reports Provider | Manage |
| Baptist Health Hardin | Newborn Screening Reports Submitter | Manage |
| BAPTIST HEALTH LAGRANGE | Newborn Screening Reports Submitter | Manage |
| BAPTIST HEALTH LAWRENCEBURG | Newborn Screening Reports | Manage |


KENTUCKY ONLINE GATEWAY
Welcome Lea Mott
My Account
Sign Out
Help
Home> Organizations > Organization Details
Details
Email Domains
Invite Users
Pending Invitations
Manage Users
Organization Details
Organization Name:
BINGHAM, GINA L.
Organization Type:
Newborn Screening Reports Provider
Source Unique ID:
1692
Organization Questions
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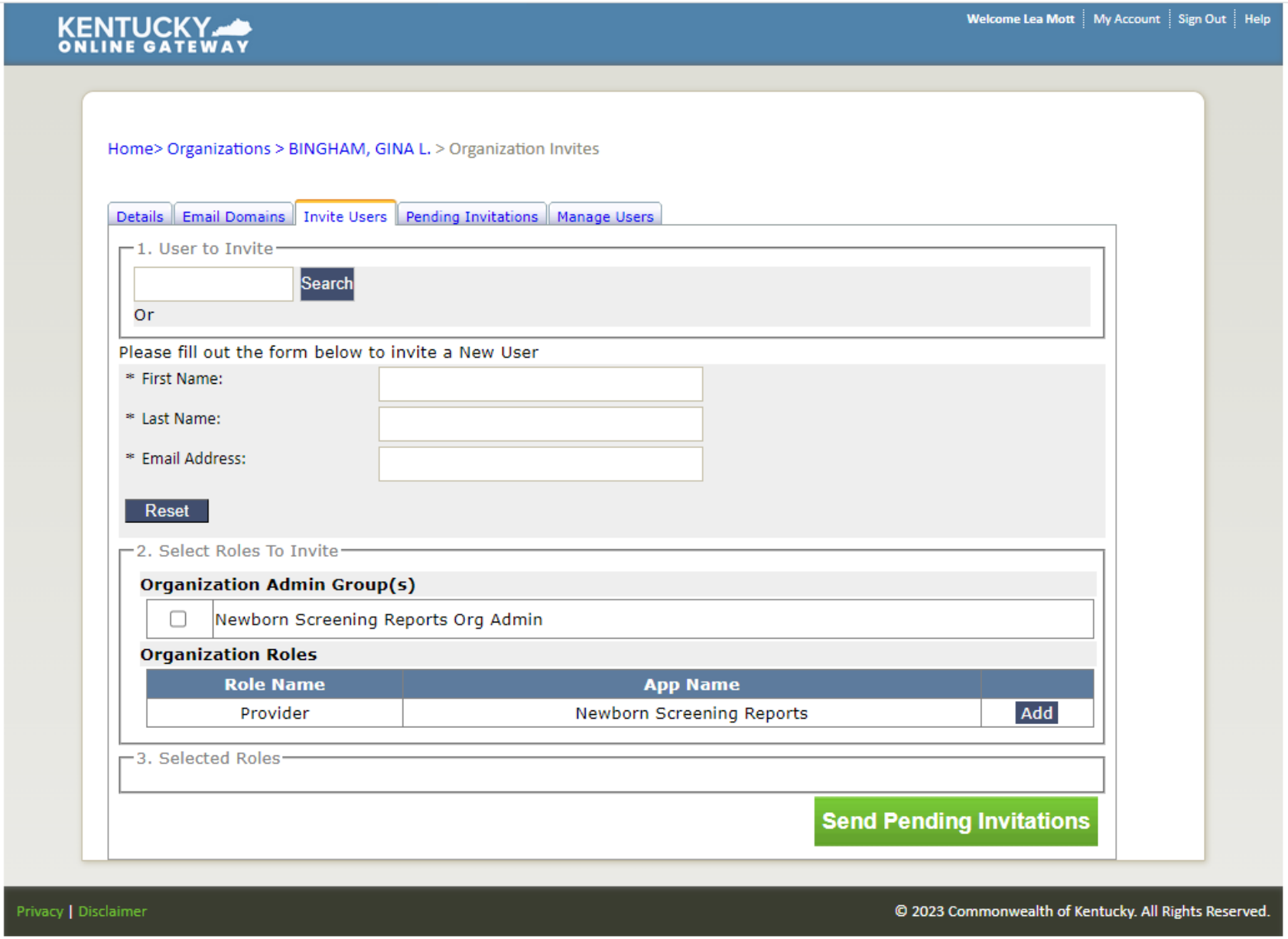
KENTUCKY ONLINE GATEWAY
Welcome Lea Mott | My Account | Sign Out | Help
Home> Organizations > BINGHAM, GINA L. > Organization Invites
Details
Email Domains
Invite Users
Pending Invitations
Manage Users
1. User to Invite
Search
Or
Please fill out the form below to invite a New User
* First Name:
* Last Name:
* Email Address:
Reset
2. Select Roles To Invite
Organization Admin Group(s)
Newborn Screening Reports Org Admin
Organization Roles
Role Name
App Name
Provider
Newborn Screening Reports
Add
3. Selected Roles
Send Pending Invitations
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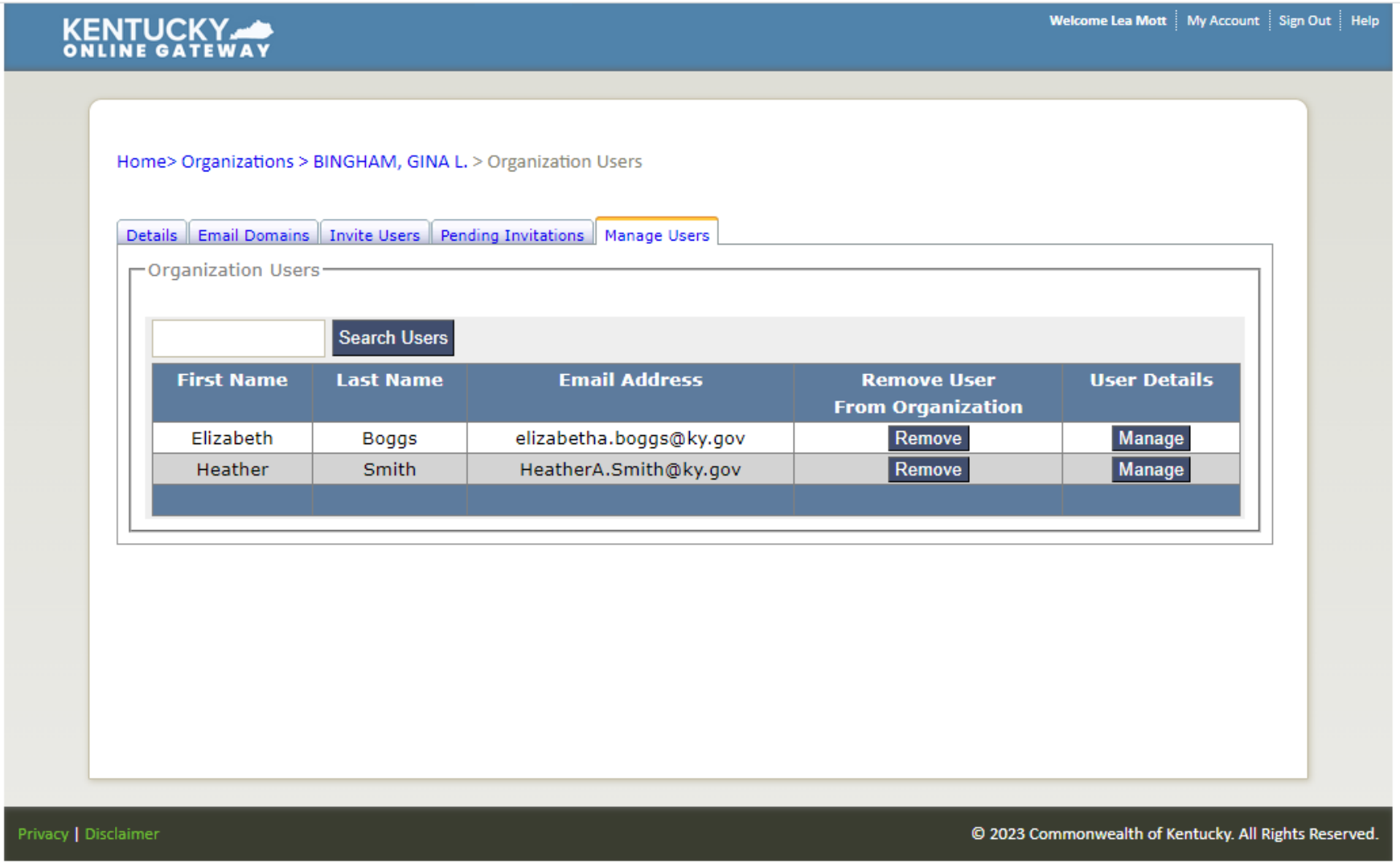
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Home> Organizations > BINGHAM, GINA L. > Organization Users
Details
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Pending Invitations
Manage Users
Organization Users
Search Users
First Name
Last Name
Email Address
Remove User From Organization
User Details
Elizabeth
Boggs
elizabetha.boggs@ky.gov
Remove
Manage
Heather
Smith
HeatherA.Smith@ky.gov
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Manage
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Kentucky.gov
Kentucky Newborn Screening Reports
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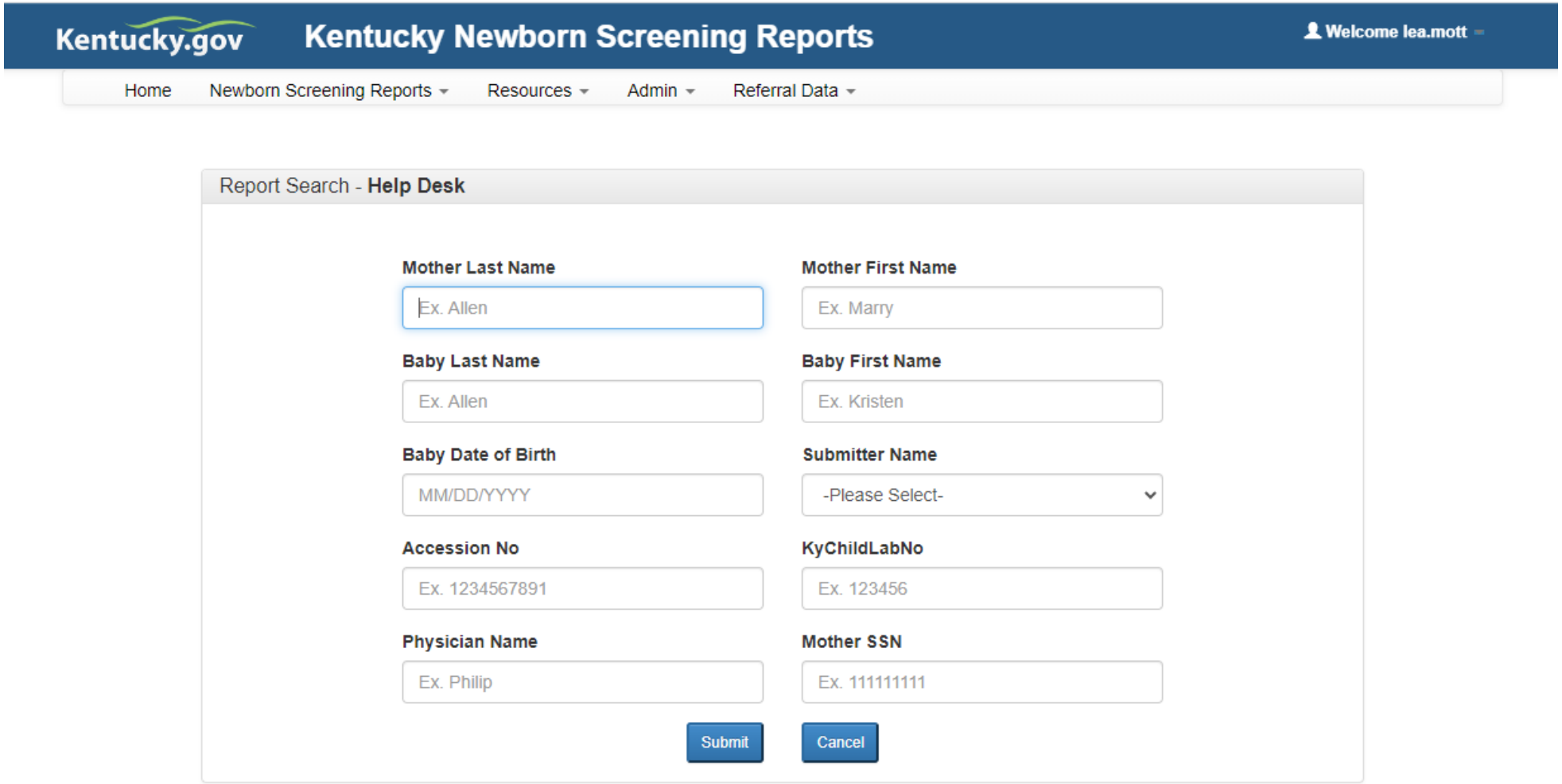
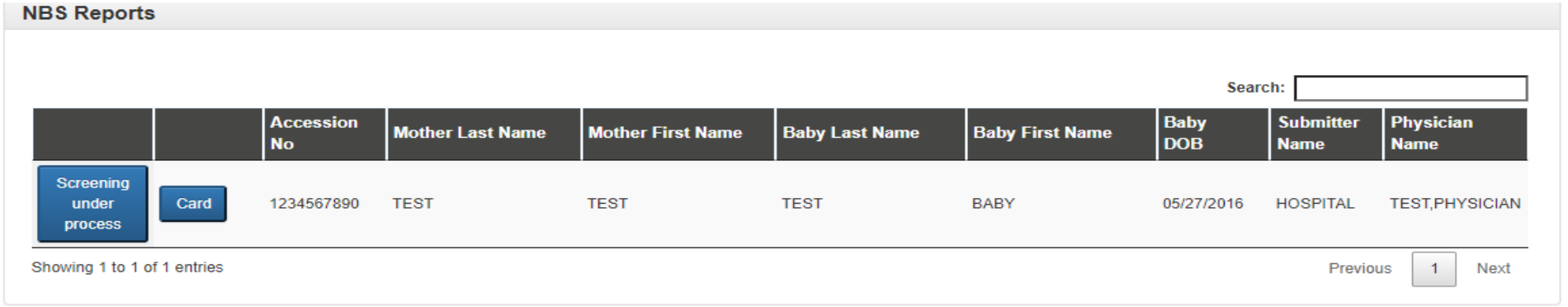
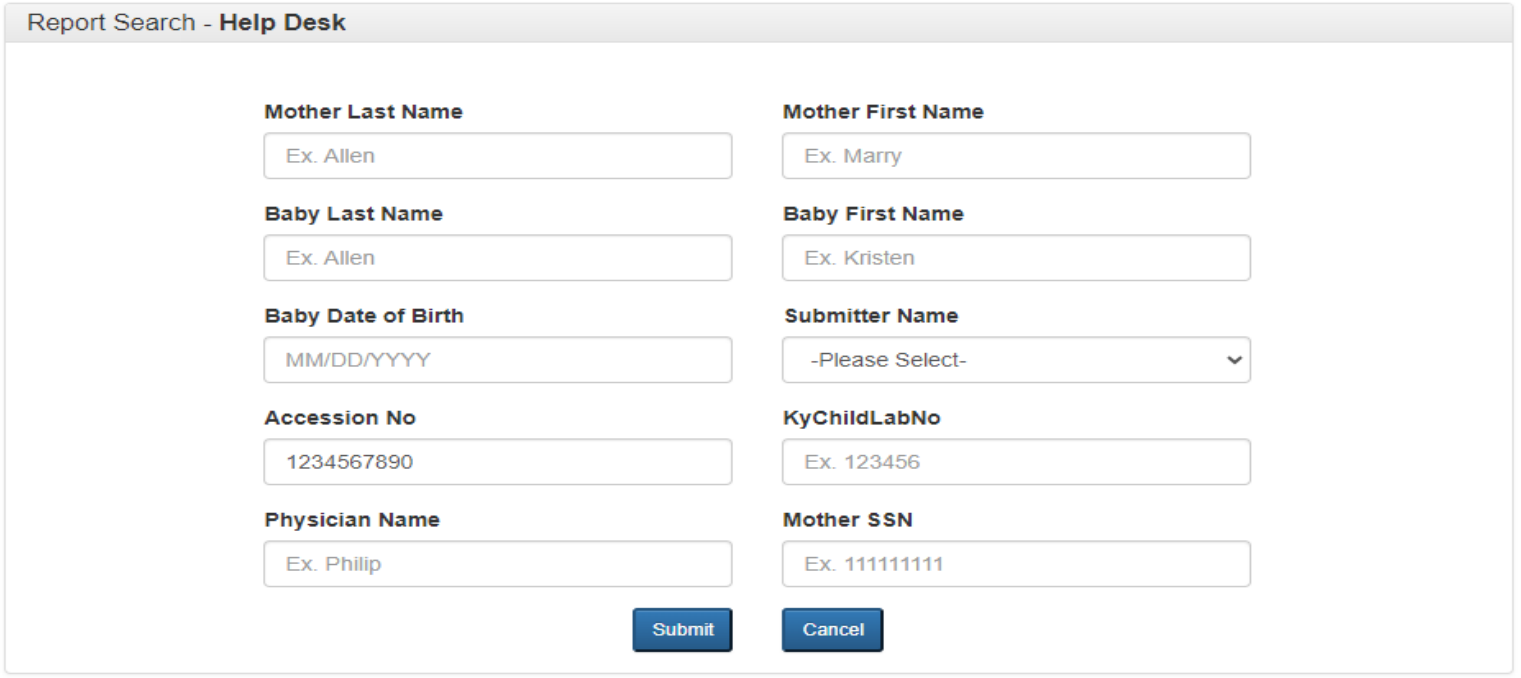
Newborn Screening Reports
Resources
Admin
Referral Data
Welcome to Kentucky Division of Laboratory Services - Newborn Screening Reports


Kentucky.gov
Kentucky Newborn Screening Reports
Welcome lea.mott
Home
Newborn Screening Reports
Resources
Admin
Referral Data
Report Search - Help Desk
Mother Last Name
Ex. Allen
Mother First Name
Ex. Marry
Baby Last Name
Ex. Allen
Baby First Name
Ex. Kristen
Baby Date of Birth
MM/DD/YYYY
Submitter Name
-Please Select-
Accession No
Ex. 1234567891
KyChildLabNo
Ex. 123456
Physician Name
Ex. Philip
Mother SSN
Ex. 111111111
Submit
Cancel


NBS Reports
Search:
Accession No
Mother Last Name
Mother First Name
Baby Last Name
Baby First Name
Baby DOB
Submitter Name
Physician Name
Screening under process
Card
1234567890
TEST
TEST
TEST
BABY
05/27/2016
HOSPITAL
TEST,PHYSICIAN
Showing 1 to 1 of 1 entries
Previous
1
Next


Report Search - Help Desk
Mother Last Name
Ex. Allen
Mother First Name
Ex. Marry
Baby Last Name
Ex. Allen
Baby First Name
Ex. Kristen
Baby Date of Birth
MM/DD/YYYY
Submitter Name
-Please Select-
Accession No
1234567890
KyChildLabNo
Ex. 123456
Physician Name
Ex. Philip
Mother SSN
Ex. 111111111
Submit
Cancel

## NBS Reports

Search:

| | | Accession No | Mother Last Name | Mother First Name | Baby Last Name | Baby First Name | Baby DOB | Submitter Name | Physician Name |
|---|---|---|---|---|---|---|---|---|---|
| Report | Card | 1234567890 | TEST | TEST | TEST | BABY | 05/27/2016 | HOSPITAL | TEST,PHYSICIAN |

Showing 1 to 1 of 1 entries

Previous 1 Next

## Report Search - **Help Desk**

**Mother Last Name**
Ex. Allen

**Mother First Name**
Ex. Marry

**Baby Last Name**
Ex. Allen

**Baby First Name**
Ex. Kristen

**Baby Date of Birth**
MM/DD/YYYY

**Submitter Name**
-Please Select-

**Accession No**
1234567890

**KyChildLabNo**
Ex. 123456

**Physician Name**
Ex. Philip

**Mother SSN**
Ex. 111111111

Submit Cancel

Control ID:
111111111
Submitter Ref. No.
111111

**KY Cabinet for Health and Family Services**
**Department for Public Health - Division of Laboratory Services (KY State Lab)**
**100 Sower Blvd Suite 204, Frankfort, KY 40601-8272**

## Newborn Screening Tests

| | | | |
|---|---|---|---|
| Mother's Name (L,F): | TEST, TEST | Baby's Name (L,F): | TEST, BABY |
| Mother's Address: | 100 MAIN ST | Date of Birth: | 5/27/16 12:54 pm |
| City, State, Zip: | CITY, KY 40004 502 XXX | Baby's Sex: | F Baby's Weight: 3,515 g |
| Mother's Phone: | XXXX | Gestation Age: | Greater than or equal to 37 Weeks |
| Mother's SSN: | XXX-XX-XXXX | Physician: | TEST, PHYSICIAN |
| Submitter: | HOSPITAL | Physician's Phone: | 1234567890 |
| Submitter's Address: | 100 N AVENUE | Physician's Address: | 100 MAIN ST |
| City, State, Zip: | CITY, KY 42701 | City, State, Zip: | CITY, KY 42701 |
| Date Reported: | Date Collected: 5/29/16 | Test Type: | Initial |

| Disorder: | Analyte: | Results: | Normal Reference Range: | Comments: |
|---|---|---|---|---|
| **Biotinidase Deficiency** | Biotinidase | Full Enzyme Activity Detected | Full Enzyme Activity | |
| **Congenital Adrenal Hyperplasia** | 17-OHP | Normal | Within Normal Limits* | |
| **Congenital Hypothyroidism** | T4,TSH | Normal | Within Normal Limits** | |
| **Cystic Fibrosis (CF)** | IRT | Normal | Within Normal Limits*** | |
| **Galactosemia** | Galactose-1-Phosphate Uridyltransferase | Full Enzyme Activity Detected | Full Enzyme Activity | |
| **Hemoglobinopathies** | Hemoglobin | Not Requested | Not Tested | |
| **Fatty Acid Oxidation Disorders** | Fatty Acids | Not Requested | Not Tested | |
| **Amino Acid Disorders** | Amino Acids | Not Requested | Not Tested | |
| **Organic Acid Disorders** | Organic Acids | Not Requested | Not Tested | |
| **SCID** | TREC | Within Normal Limits | TREC Within Normal Limits | |
| **Lysosomal Storage Disorders** | Lysosomal Enzymes | Full Enzyme Activity Detected | Full Enzyme Activity**** | |

*Congenital Adrenal Hyperplasia-17OHP normal weight-based limits for all initial specimens and repeat specimens on infants less than one week old: <1500g, <70 ng/mL; 1500g-2500g, <40 ng/mL; >2500g, <25 ng/mL. Normal limit for repeat specimens on infants greater than one week old of any weight is <25 ng/mL. Treatment of the mother or the child with steroids may result in false negative results.
**T4- Normal for specimens from infants < 4 weeks of age is 5-27 µg/dL. Normal T4 for specimens from infants > or = 4 weeks of age is 5-19 µg/dL. Normal TSH is <20µU/mL. TSH values below 2.91, the lower limit of linearity for this method, will be reported as <2.91. Rare hypothalamic and pituitary disorders may be causes of fatal hypothyroidism with low TSH and low T4. Neonates born to women with Graves' disease may have fatal hyperthyroidism with low TSH and normal/elevated T4. Recommend clinical correlation and follow up as indicated.
***IRT - Normal for initial specimens from infants < 4 weeks of age is <58 ng/mL. IRT - Normal for initial specimens from infants > or = 4 weeks of age is <50 ng/mL. IRT - Normal for repeat specimens (regardless of age) is <50 ng/mL. Meconium Ileus may result in false negative results.
****Enzyme activities of galactocerebrosidase, acid alpha-glucosidase, and alpha-L-iduronidase. Testing performed at Mayo Medical Laboratories, 3050 Superior Drive NW, Rochester, MN 55901.

-Specimen source: dried blood spots.
-This report contains patient information that must be protected in accordance with the Health Insurance Portability and Accountability Act.
-Analyte Specific Reagent: The Severe Combined Immunodeficiency assay was developed and the performance characteristics determined by Kentucky Division of Laboratory Sevices. It has not been cleared or approved by the U.S. Food And Drug Adminsitration.

Jeremy Hart MD, FCAP
Director - (502) 564-4446

Vaneet Arora MD MPH
Associate Director - (502) 564-4446



**TEST HOSPITAL ATTENTION:**
**NURSERY**
**100 N AVENUE**
**CITY, KY 42701**

**TESTS CONDUCTED:**

**Enzyme Immunoassay**: Congenital Adrenal Hyperplasia (CAH), Congenital Hypothyroidism (CH), Cystic Fibrosis (CF), Galactosemia (GALT), Biotinidase (BIO)

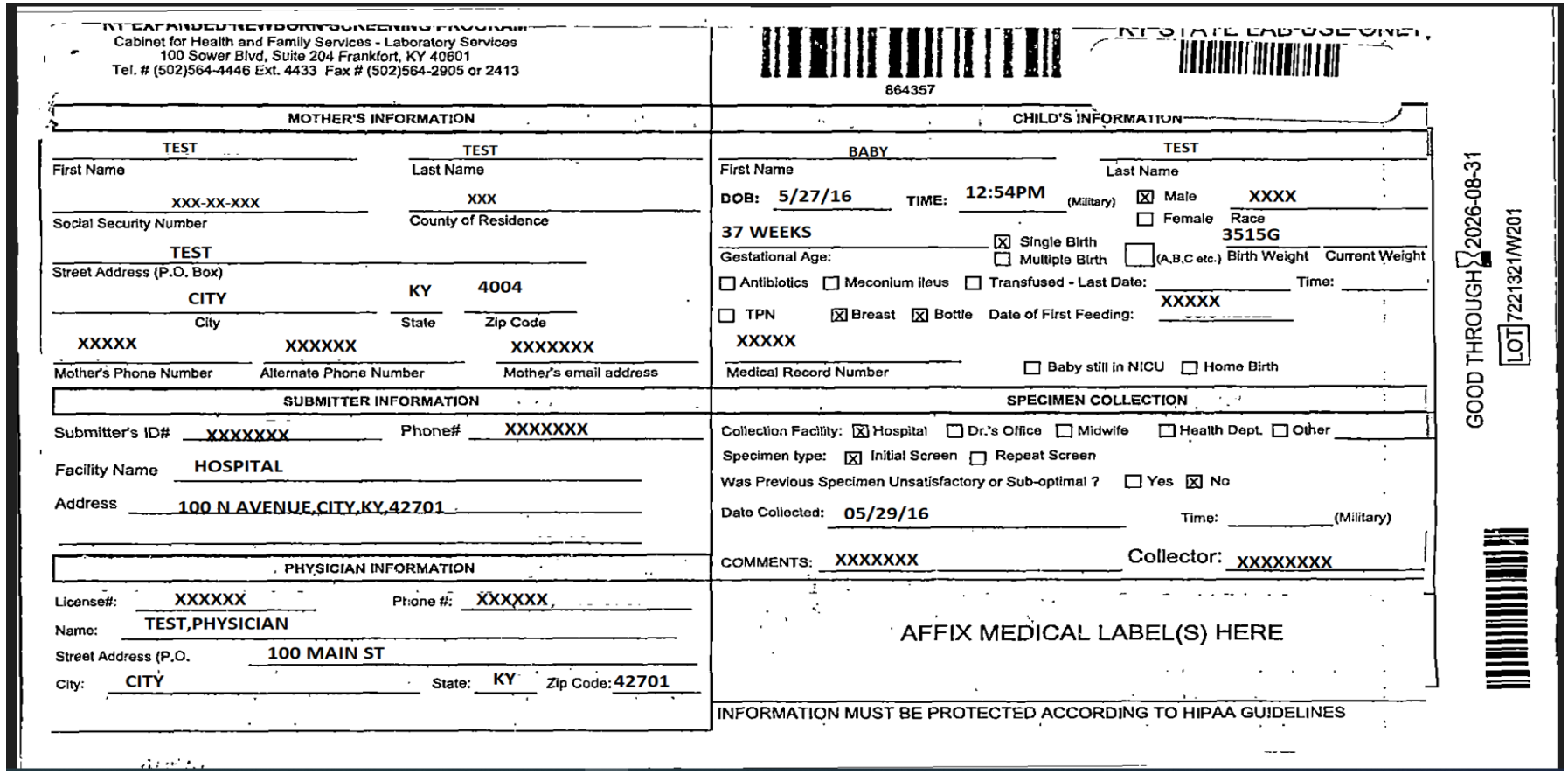
**High Performance Liquid Chromatography (HPLC)**: Hemoglobinopathies

**Tandem Mass Spectrometry (MS/MS):**
***Fatty Acid Oxidation Disorders:*** Medium-chain acyl-CoA dehydrogenase deficiency (MCADD), Very long-chain acyl-CoA dehydrogenase deficiency (VLCADD), Long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHADD), Trifunctional protein deficiency (TFP), Carnitine uptake defect (CUD), Carnitine acylcarnitine translocase deficiency (CACT), Carnitine palmitoyl transferase I deficiency (CPT-I), Carnitine palmitoyl transferase II deficiency (CPT-II), Glutaric acidemia type II (GA-II), Short-chain acyl-CoA dehydrogenase deficiency (SCADD)
***Amino Acid Disorders:*** Argininosuccinic acidemia (ASA), Citrullinemia Type I (CIT-I), Tyrosinemia Type I (TYR-I), Maple syrup urine disease (MSUD), Homocystinuria (HCY), Phenylketonuria (PKU), Argininemia (arginase deficiency) (ARG), Citrullinemia Type II (CIT-II), Hyperphenylalaninemia (H-PHE), Hypermethioninemia (MET), Tyrosinemia Type II (TYR-II), Tyrosinemia Type III (TYR-III), Nonketotic Hyperglycinemia (NKHG)
***Organic Acid Disorders:*** Beta-ketothiolase deficiency (BKT), Isovaleric acidemia (IVA), Glutaric acidemia Type I (GA-I), 3-Hydroxy-3-methylglutaric aciduria (HMG), Multiple carboxylase deficiency (MCD), 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC), Methylmalonic acidemia (MMA Cbl A, B, C, D), Methylmalonyl-CoA mutase deficiency (MUT), Propionic acidemia (PA), 2-Methyl-3-Hydroxybutyric aciduria (2M3HBA), 3-Methylglutaconic aciduria (3MGA), Isobutyryl-CoA dehydrogenase deficiency (IBD), Malonic acidemia (MAL), Ethylmalonic encephalopathy (EE), 2-Methylbutyryl-CoA dehydrogenase deficiency(2MBDH)

**Real-Time Polymerase Chain Reaction (PCR):** T-Cell Receptor Excision Circles (TREC) for Severe Combined Immunodeficiency

**Flow Injection Analysis-Tandem Mass Spectrometry:**
***Lysosomal Storage Disorders:*** Krabbe Disease, Pompe Disease, Mucopolysaccharidosis Type I (MPS I) [Testing performed at Mayo Medical Laboratories in Rochester, MN]

**The laboratory values in this report represent screening test results and are intended to identify infants at risk for selected disorders and in need of more definitive testing. The above results should be correlated clinically with consideration of age at the time of collection, nutrition, birth weight, prematurity, health status, and treatments. It is very important for physicians to be aware that a negative screening result does not indicate with certainty the absence of the above listed disorders. The physician should be alert to the clinical symptoms of these conditions, so that diagnosis and treatment can take place as early as possible in infants who are not identified through the newborn screening program.**



KY EXPANDED NEWBORN SCREENING PROGRAM
Cabinet for Health and Family Services - Laboratory Services
100 Sower Blvd, Suite 204 Frankfort, KY 40601
Tel. # (502)564-4446 Ext. 4433 Fax # (502)564-2905 or 2413

KY STATE LAB USE ONLY

864357

**MOTHER'S INFORMATION**

TEST — First Name
TEST — Last Name
XXX-XX-XXX — Social Security Number
XXX — County of Residence
TEST — Street Address (P.O. Box)
CITY — City
KY — State
4004 — Zip Code
XXXXX — Mother's Phone Number
XXXXXX — Alternate Phone Number
XXXXXXX — Mother's email address

**SUBMITTER INFORMATION**

Submitter's ID# XXXXXXX Phone# XXXXXXX
Facility Name HOSPITAL
Address 100 N AVENUE,CITY,KY,42701

**PHYSICIAN INFORMATION**

License#: XXXXXX Phone #: XXXXXX
Name: TEST,PHYSICIAN
Street Address (P.O. 100 MAIN ST
City: CITY State: KY Zip Code: 42701

**CHILD'S INFORMATION**

BABY — First Name
TEST — Last Name
DOB: 5/27/16 TIME: 12:54PM (Military) ☒ Male ☐ Female XXXX — Race
37 WEEKS — Gestational Age: ☒ Single Birth ☐ Multiple Birth ☐ (A,B,C etc.) 3515G — Birth Weight — Current Weight
☐ Antibiotics ☐ Meconium ileus ☐ Transfused - Last Date: Time:
☐ TPN ☒ Breast ☒ Bottle Date of First Feeding: XXXXX
XXXXX — Medical Record Number ☐ Baby still in NICU ☐ Home Birth

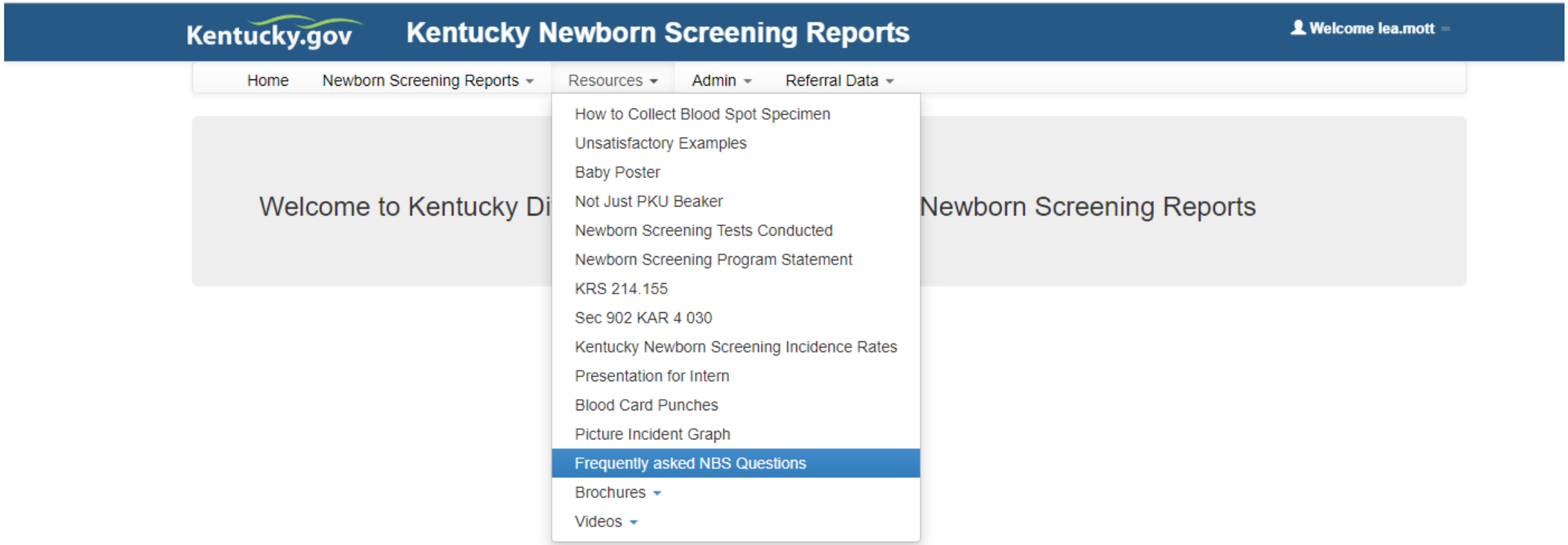
**SPECIMEN COLLECTION**

Collection Facility: ☒ Hospital ☐ Dr.'s Office ☐ Midwife ☐ Health Dept. ☐ Other
Specimen type: ☒ Initial Screen ☐ Repeat Screen
Was Previous Specimen Unsatisfactory or Sub-optimal ? ☐ Yes ☒ No
Date Collected: 05/29/16 Time: (Military)
COMMENTS: XXXXXXX Collector: XXXXXXXX

AFFIX MEDICAL LABEL(S) HERE

INFORMATION MUST BE PROTECTED ACCORDING TO HIPAA GUIDELINES

GOOD THROUGH 2026-08-31
LOT 7221321/W201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Referral Data
How to Collect Blood Spot Specimen
Unsatisfactory Examples
Baby Poster
Not Just PKU Beaker
Newborn Screening Tests Conducted
Newborn Screening Program Statement
KRS 214.155
Sec 902 KAR 4 030
Kentucky Newborn Screening Incidence Rates
Presentation for Intern
Blood Card Punches
Picture Incident Graph
Frequently asked NBS Questions
Brochures
Videos
Welcome to Kentucky Di
Newborn Screening Reports

# Thank You!
# Questions & Comments

**Lea Mott,**
Newborn Screening
Lea.mott@ky.gov