

KANSAS NEWBORN SCREENING ADVISORY COUNCIL MEETING

ONLINE VIA ZOOM MEETING

MINUTES

JANUARY 19, 2023

Members Present

Dr Carolina Beltran, Julie Wellner, Dr Kourtney Bettinger, Dr Mike Lewis, Karey Padding, Michelle Leeker, Dr. Thomas Loew, Meghan Strenk, Shobana Kubendran, Dr. Britton Zuccarelli, Julie Wellner,

Members Absent

KDHE Staff Present

Michelle Black, Drew Duncan, Kinsey Anderson, Michelle Mills, Phillip Davis, Marilee Lowrey, Phil Adam, Connie Neuhofer, Shane Morris, Karla Morcado Morales, Austin Weaver, Tyler Brinlee, Blake Fosburg, Justin Gianares, Elizabeth Schardine, Eliot Kemper, Blake Fosburgh, Zach Leeker, Oliva Morris, Christine Houston, Paul Harrison, Sally Brownlee, Slater Champlin, Hanna Radke,

Others Present

Charlotte Buchanan, Gail Webster, Karen Braman, Meghan Strenk, Kirsten Finn, Gail Webster, Dr. Laurie Gwyn, Dr. Bryce Heese, Karen Braman, Kristen Finn, Miranda McAuliffe, Monica Davis, Zac Leeker, Paul Roesch, Dr. Laurie Gwen, Ashley Bates-Crowley

ACITON ITEMS:

Minutes –

Minutes from September were reviewed.

Dr. Loew moved to approve the minutes and Meghan Strenk seconded.

Action Items-

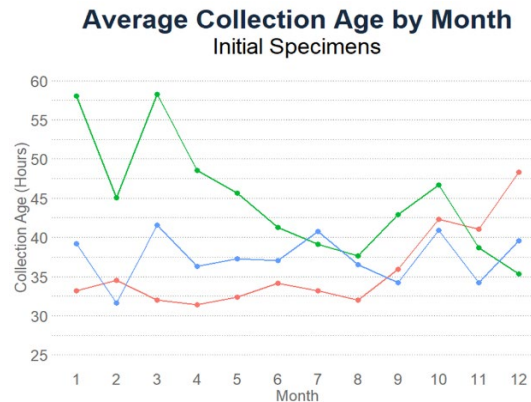
1. General Updates-

- i. Data System Update
 - i. RFP for data system
 - ii. Continue to utilize work arounds
- ii. Legislative Updates – Presenting an NBS bill again this year to expand funding in hopes of keeping up with the RUSP.
- iii. APHL Conference

- iv. Staffing Updates
 - v. F/U Staff -
 - vi. Lab Staffing – question was asked how we compare to lab staff in other states that compare to KS. Michelle Mills did not know how we compare. KHEL has done a review of what staff would be needed to support expanded screening. Our staff are cross trained but it takes a year or two for an analyst to be fully trained.
 - vii. HRSA NBS Propel Grant – In the process of applying for the grant.
 - viii. New Mission and Vision Statements- Provided to participants.
2. **Staffing-**
- i. KHEL
 - i. Christine Houston – Health Chemistry Section Chief
 - ii. Myron Gunsalus – Lab Director is resigning.
 - ii. NBS Laboratory
 - i. Assistance from COVID employees - 2 full-time and one part-time staff
 - ii. Two temporary employees added July and August 2022
 - iii. Six full-time KDHE employees
 - iv. Holding one full-time employee position
 - v. Holding Technical Supervisor position
3. **Screening and Surveillance section in the BFH New Mission and vision statements.**
- i. **Vision-** *Improve quality of life and health outcomes*
 - ii. **Mission-** *Through a data-driven approach and relationship building, Kansas Screening and Surveillance strives to improve equitable access to information, services and support for newborns, mothers and families.*
4. **APHL 2022 Newborn Screening Symposium**
- i. Michelle Mills served on the planning committee, session moderator
 - ii. 1 Poster (Michelle Mills)
 - iii. 3 Presentations (Michelle Mills, Drew Duncan, Kinsey Anderson)
 - iv. Presentations and Posters:
 - i. Michelle Mills: Overnight Shipping Trial for Midwives and Smaller Facilities to Improve Transit Time from Collection to Receipt for the State of Kansas Newborn Screening Program
 - ii. Drew Duncan: Building Relationships to Reduce the Gaps: How Analysis of LFU Data Led to Newfound Partnerships, a More Comprehensive Educational Program, and Increased Equity Within Program Activities
 - iii. Kinsey Anderson: Using Systems Design Thinking to Improve Internal Notifications Between Laboratory and Follow-up Components of the Kansas Newborn Screening Program, Part 1: Understanding the Current System, User Needs and Improvement Measures

5. Data Discussion –

i. Collection Age



i.

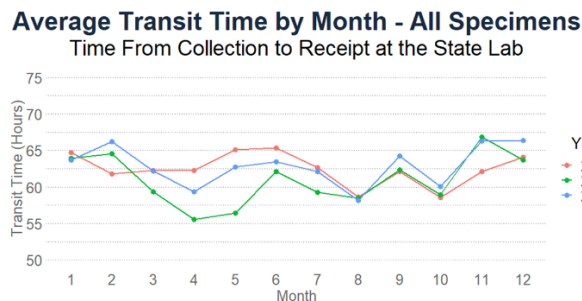
1. Most notable fluctuations align with:
2. Decrease in education activities in late 2020 and early 2021
3. COVID-19 waves (by visual inspection)

ii. 2022 has been much more steady and near pre-pandemic Collection Ages

iii. Average Hours

1. 2020- 35.8 Average Hours
2. 2021 44.8 Average Hours
3. 2022 37.5 Average Hours

ii. Transit Time



i.

ii. Activities for Improvement

1. APHL Sunday Courier Project began August 2020
2. Continued Fed-Ex Shipping Labels for Midwives
3. Still greatest positive impact overall

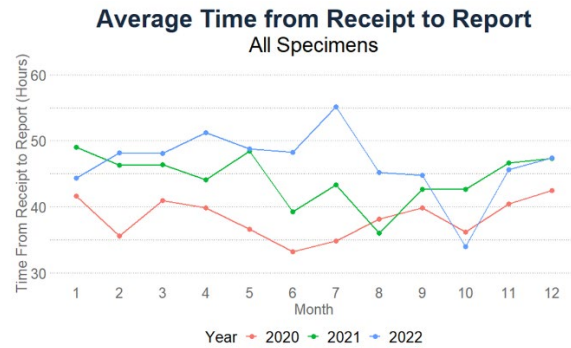
iii. Impactful Events

1. Hospital staffing shortages and turnover
2. Seasonal shipping delays with winter weather

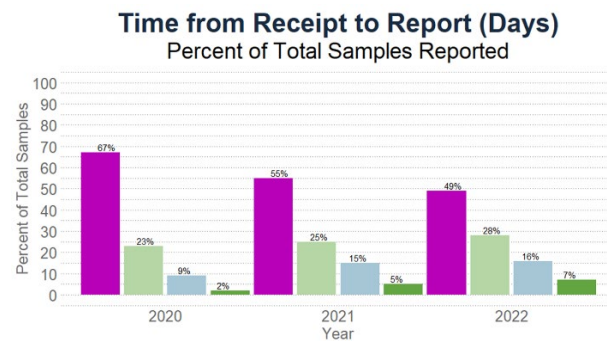
iv. Averages

1. 2020 - 62.4 Average Hours (2.6 Days)
2. 2021 - 60.9 Average Hours (2.5 Days)
3. 2022 – 62.9 Average Hours (2.6 Days)

iii. Time from Receipt to Report



- i.
- ii. Period in 2022 where lab stopped running same-day confirmations due to low-staff
- iii. August 2022 – began running LSD everyday instead of batching
- iv. September 2022 – Staffing levels returned to normal
- v. Average Times
 1. 2020 – 38.3 Average Hours (1.6 Days)
 2. 2021 – 44.2 Average Hours (1.8 Days)
 3. 2022 – 46.5 Average Hours (1.9 Days)
- iv. Percent of All Specimens Reported in Given Timeframes



- i.

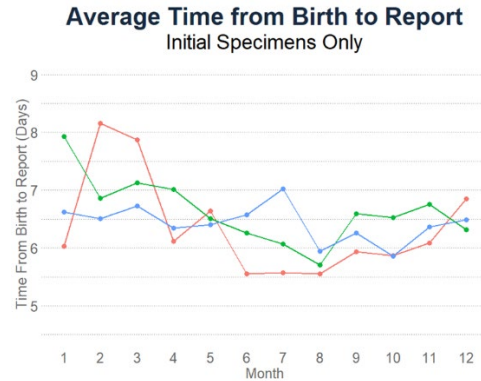
Report Time

< 2 Days

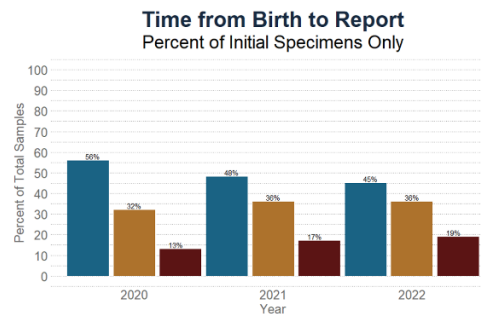
2 Days

3 Days

>= 4 Days
- ii.
- v. Time from Birth to Report *Definition: Time from birth to when final report is released by the laboratory's information system (excludes repeat specimens and specimens with amended reports)*



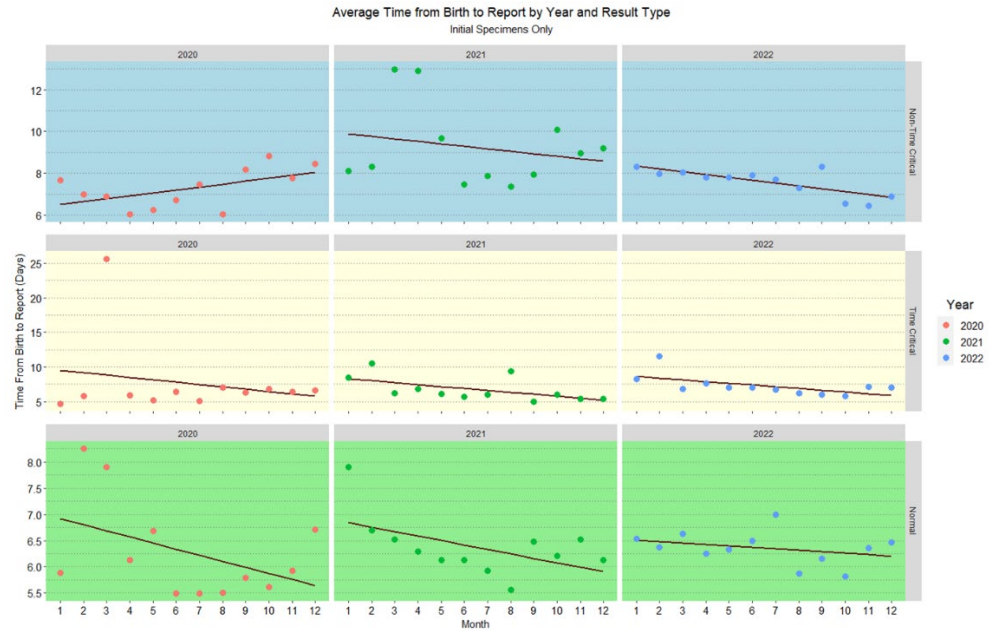
- i.
- ii. Winter weather causes shipping delays – samples received after laboratory cutoff times
- iii. Slight increase in 2021
 1. Addition of Lysosomal Storage Disorders
 2. Increased collection ages
- iv. 2022 fluctuations reflect Receipt to Report fluctuations
 1. Staff shortages
 2. Stopped batching LSDs
- v. Averages
 1. 2020 – 150.0 Average Hours (6.3 Days)
 2. 2021 -157.0 Average Hours (6.6 Days)
 3. 2022 – 153.7 Average Hours (6.4 Days)
- vi. Percent of Initial Specimens Reported in Given Timeframes



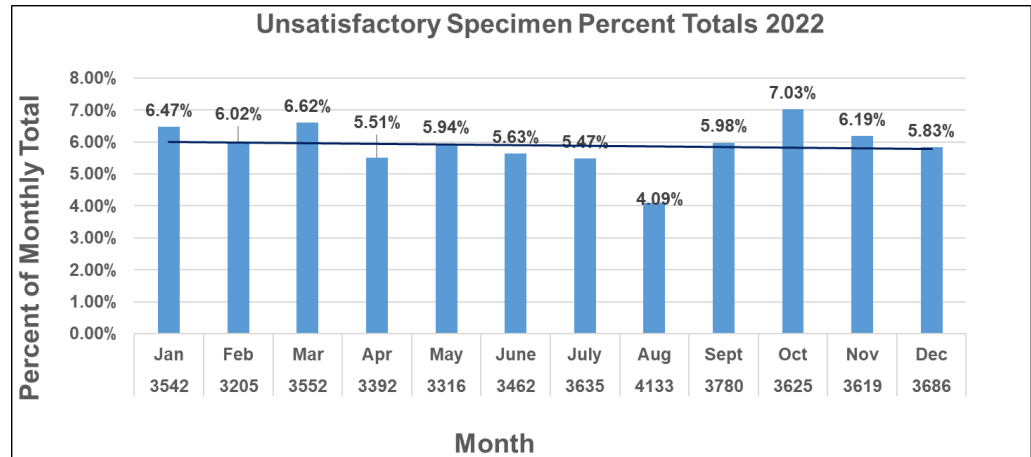
- i.
- ii. Changes between years likely related to:
 1. The increased collection age in early 2021
 2. Increased transit times in 2021/2022
 3. Slight, temporary increase Receipt to Report times in 2022
- iii.

Report Time

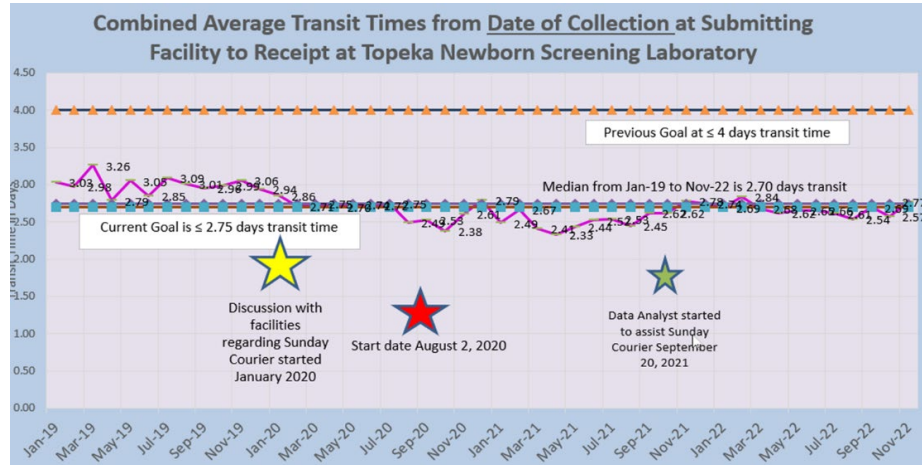
 - <= 5 Days
 - 6-7 Days
 - 8+ Days
- vii. Non-Time Critical VS Time Critical



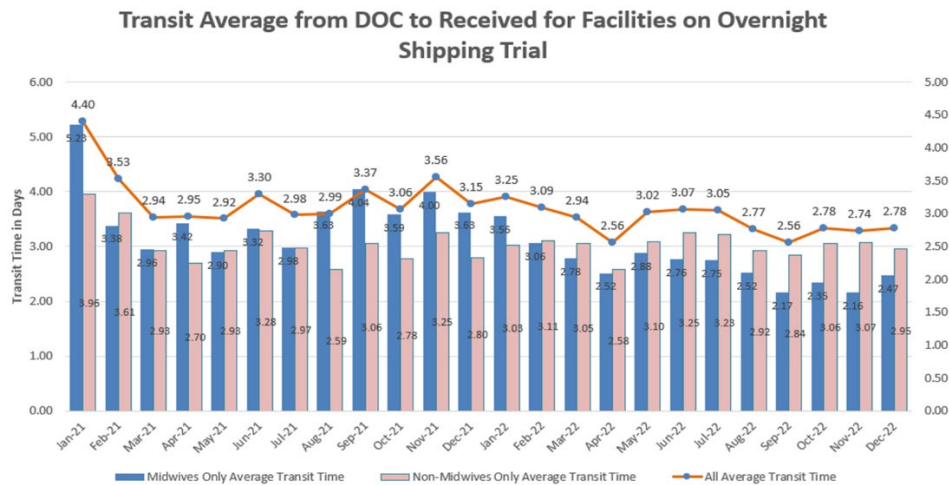
- i.
- ii. Non-time Critical reporting times
 1. Increased between 2020 and 2021 – likely addition of LSDs
 2. Steady decrease since 2021
- iii. Time Critical reporting times
 1. Steady from year to year
 2. Seem to decrease throughout the year
- iv. NTC v. TC v. Normal
 1. Normal specimens take the least amount of time to report
 2. No significant difference between NTC and TC
- v. Note: Times reflect when KHEL's report is released, not when results are called out or when the individual analysis is complete.
- viii. Dr. Beltran asked if we could look at Time Critical results in a different way.
 - i. Her concern is that they are sometimes not being notified by the PCP until 3 or 4 days after following up has notified the PCP.
 - ii. Dr. Hesse commented that there is not a referral system in place, and it should not be on follow up or a non-biochemical staff to make the determination on follow up needs.
 - iii. We will come back to this discussion at the end of this meeting.
- ix. Unsatisfactory Specimens



- i.
6. **KHEL Updates**
 - i. Recommended Uniform Screening Panel
 - i. The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) met November 3 -4, 2022.
 - ii. Mucopolysaccharidosis II (MPS II) was added to the Recommended Uniform Screening Panel (RUSP) by the Secretary of the U.S. Department of Health and Human Services in August 2022.
 - iii. Guanidinoacetate Methyltransferase (GAMT) Deficiency was added to the Recommended Uniform Screening Panel (RUSP) by the Secretary of the U.S. Department of Health and Human Services this month, January 2023.
 - iv. Krabbe was unanimously voted to move forward for full evidence review for consideration for RUSP inclusion status.
 - v. A nomination packet has been submitted for Duchenne's Muscular Dystrophy to the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) on June 29, 2022. The Nomination and Prioritization Workgroup is reviewing the nomination.
 - vi. ACHDNC had a discussion in February 2022 to increase the capacity of reviewing multiple nominations per year. The committee will be forming a workgroup to look at the capacity of the committee and capacity of the NBS system. This workgroup will develop a criteria and a process for prioritizing the review of nominated conditions.
 - ii. Next ACHDNC meeting is February 9 – 10, 2023
7. Sunday Courier Grant



i.



ii.

- iii. Julie commented that she understood that it was the A/C job to review and recommend with conditions should be implemented by KS
- iv. Paul Harrison recommended to we rank with conditions we would like to prioritize bringing on to the panel.
- v. Dr. Beltran asked if it would be the whole committee or a subcommittee. Kinsey stated it should be the whole committee. Dr. Beltran agreed that we needed to discuss what is feasible for both the lab and follow up.
- vi. Michelle Mills gave an update on KHEL preparing to bring on new conditions. 11:30 time on computer.
- vii. Kisney will summarize and send out an email after todays meeting.

8. 15 Minute Break.

9. Follow up Updates

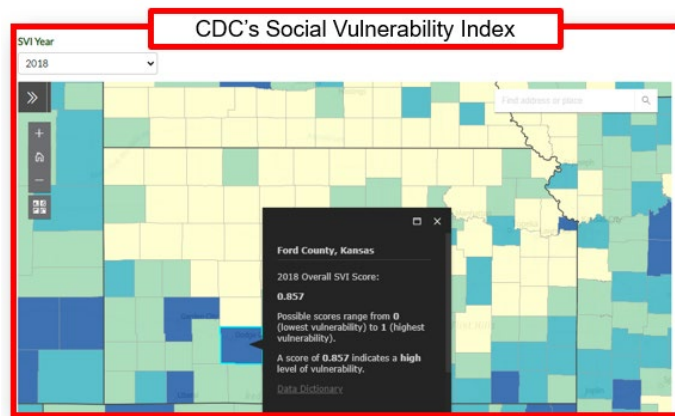
- i. Consultation Contracts
 - i. Metabolic and Genetic Specialists - focusing on first
 - ii. Internal review of PD happening now
- ii. Medical Director Contributions
 - i. Support w/Consultation Contracts

- ii. Provides PCP and clinical perspective
 - iii. Resource when cases don't follow protocol
 - iv. Opens up time for Program Director
- iii. New Parent letters
 - i. Invalid HGBs
 - ii. Infants without a screen
 - 1. MB stated if facility's have refusal form, to please send them to us
 - 2. Paul Harrison noted the NBS cards now have refusal on the back
- iv. Comprehensive Letter Review
 - i. Internal Review > Stakeholder Input > Implement Changes
 - ii. Parent Documents
 - 1. Parent Letter
 - 2. Disorder Information Sheets for families
 - 3. Revised for health literacy accessibility, clarity, situational and conditional information
 - 4. Internal review is complete, and the next step is to get parent feedback. Then will be sent to Communications for approval.
 - a. KA - Hopefully will be done in time to enter into new data system
 - b. Ashley Bates-Crowley – asked for confirmation that parents will be looking at letters for language, etc., KA confirmed
 - c. Ashley Bates-Crowley – asked who will be in focus groups. KA replied they are not formed yet, but she will be calling Ashely and they will be diverse
 - d. Kirsten Finn asked if f/u program connects newly diagnosed babies families w/previously diagnosed babies families. KA- Other support services do that; Zach – SHCN has care coordination, direct services, and special requests, and one-time diagnosis testing; Karey Padding noted once referred to CF clinic, then offered other family connection resources
 - e. KA noted that family connections or where PCP's can point families for resources should be kept in mind as reviewing both parent and provider documents
 - f. Ashely Bates-Crowley – noted that sometimes organizations are only in a certain area and cannot provide assistance, so need to find true community partners; suggested champion. KA will take over to MCH area

- iii. Provider Documents
 - 1. PCP letter
 - 2. Disorder Report Forms
 - 3. Disorder Information Sheets for Providers
 - 4. ACT Sheets
 - 5. Algorithms
- iv. Re-evaluated w/in larger context of Program's protocol of communicating abnormal results as how we communicate dictates what kind of documents, we create
- v. First step is a focus group and user feedback
 - 1. KA – Accenture will be supporting this process

10. Education and Outreach Updates

- i. Facility Outreach
 - i. Increasing visits to hospitals, clinics and labs in 2023.
 - 1. SM - Visiting 1-3 facilities/month
 - 2. SM -Contacted all hospital, birthing centers, & midwives by e-mail, phone, or personal contact
 - ii. Distribution of Guide to Kansas Family Supports continues.
 - iii. Targeting more vulnerable areas first.



- iv.
 - ii. Guide to KS Family Support
 - i. Hospital and Birthing Centers
 - 1. Over 3,000 pamphlets have been mailed/delivered to various hospitals.
 - 2. 50 to 300 pamphlets per location
 - ii. Notable Locations
 - 1. Goodland
 - 2. Overland Park
 - 3. Hays
 - 4. Seneca
 - 5. McPherson

6. Garden City
 7. Hutchinson
 8. Manhattan
- iii. Other Locations
 1. Over 8,000 pamphlets have been mailed/delivered.
 2. Average of 25 to 100 pamphlets per location.
- iv. Location Types
 1. Public Libraries
 2. Work Centers
 3. Care Centers
 4. Charities
 5. Health Dept.
 6. DCF
 7. Goodwill
 8. Housing Authority.
- iii. Newsletter Numbers and Updates –
 - i. Average Open rate of 36% for all of 2022
 - ii. Open rate up by 1.2% from 2021
 - iii. Total of 259 subscribers
 - iv. Name will not be changed for 2023
 1. Ashley Bates-Crowley suggested asking what the newsletter means to those that read it and that might help come up w/a new inclusive name
- iv. Third Annual Awards Program
 - i. Announced October 15, 2022
 - ii. Most clicked newsletter article in October
 - iii. 3 All Around Best of the Best Winners
 - iv. 5 Best of the Best in Metabolic/Genetic Screening
 - v. 9 Best of the Best in Point of Care Screening
 1. Ashley Bates-Crowley asked how these were reviewed and decided upon; KA showed awards booklet and explained
 2. Ashley Bates-Crowley suggested adding Education of families to Best of the Best, prenatal and postnatal, and suggested contacting Dr. Ebony; KA notes it probably won't happen for 2023, but they will look into it
- v. 2021 Best of the Best

Facilities Earning “All Around Best of the Best” Recognition
(4 or more Categories)

Hutchinson Regional Medical Center

*CCHD Screening | Hearing Screening | Metabolic & Genetic Screening Honorable
Mention for Collection Age, Transit Time, and Unsatisfactory Rate*

Nemaha Valley Community Hospital

*CCHD Screening | Metabolic & Genetic Screening Collection Age Top Honors and
Honorable Mention for Transit Time and Unsatisfactory Rate*

Neosho Memorial Hospital

*CCHD Screening | Hearing Screening | Metabolic & Genetic Screening Honorable
Mention for Collection Age and Unsatisfactory Rate*

i.

Facilities Meeting Both Point-of-Care Screening Metrics

Bloom Midwifery and Lactation

Cheyenne County Hospital

Geary Community Hospital

Herington Hospital, Inc.

Life Center Clinic

Morris County Hospital

New Birth Company Overland Park

Norton County Hospital

Washington County Hospital

ii.

Facilities Earning Recognition in all Metabolic Screening Categories

~~AdventHealth~~ Shawnee Mission

Ascension Via Christi Hospital - Manhattan

Stormont Vail Health

University of Kansas Medical Center

Wesley Medical Center

iii.

iv. Facility Recognitions Redesigns

1. Facility recognition will be redesigned for 2023
2. Adding success stories
3. Refreshed new look (will work with graphic designer)
4. Possible in person event to give out awards.
 - a. MM asked if these are virtual; SM – yes, but facilities like the printed version as well
 - b. SM mentioned adding success stories; KA added photo submissions, as well
 - c. SM mentioned possibility of parents going to awards distributions to share their NBS stories.
 - d. Dr. Beltran suggested we have **action item** to review this topic again

vi. Wyandotte County Health and resource fair

- i. Hosted resource fair for local community
- ii. 21 different booths/participants

1. SM - Ex. Were dental booth, Covid shots, handed out Covid tests, flu shots, etc.
2. SM - KC mayor showed up!
3. SM - Successful and positive – will be doing every year

vii. Additional Activities

- i. Vanity Website for Screening & Surveillance
 1. SA – middle of this year is the goal to have completed
- ii. Possible YouTube channel
 1. Training Videos
 2. Short Clips for Frequently Asked Questions
 - a. SA – Using VMO now and not as user friendly
 - b. Gail Webster commented that this could be used as part of a provider's informed consent education efforts
 - c. Paul Harrison suggested Lab Exchange video
- iii. Interactive map for outreach tracking
- iv. Updating Newborn Screening brochure
 1. Will include translation into multiple languages
 2. Double sided (English/Spanish)

11. Comments/Discussion

- i. Paul Harrison – Lab Exchange
 - i. electronic ordering system as well as electronic entry;
 - ii. will provide portal for all providers; login and search for baby/mom to get NBS report
 - iii. ordering is mobile friendly and has drop down options
 - iv. transfers automatically, so less human error
 - v. reporting portal for State goes live March 1, 2023
- ii. Kinsey Anderson – Office Info/Updates
 - i. Office Hours - Showed how to log in on website
 - ii. Phone tree

12. New Business

- i. Time Critical Results – In what situation should we be making it a practice to make sure Specialist has been called w/in a day. What safety net do we need to be sure no one is being overwhelmed?
 - i. Want to make sure we are not sharing pt information if not necessary
 1. Dr. Beltran – need to communicate that condition is time critical
 2. MB – do we need to call Specialist for every refer?
 - a. Dr. Beltran – we don't have to have a perfect plan today; sometimes they may be waiting for report

3. MB – are you only struggling w/PCP's or w/NICU's as well. Dr. Beltran replied she is specifically talking about PCP's outside of NICU.
4. MB asked if stakeholders feel they can get information from f/u in a timely manner. Julie Wellner replied that it depends on the time of day. Many times they are contacted by NICU's or PCP's at the end of the day.
 - a. KA commented that the portal Paul talked about will be available to Specialists as well, but that won't have f/u info.
 - b. MB commented that they can always call KHEL and MM confirmed.
 - c. Meghan Strenk commented that f/u is really responsive.
 - d. KA commented how this falls under the comprehensive letter review
 - e. ML suggested case review to find out when we need to f/u to be sure Specialists were contacted and how we may need to change our wording
 - f. Dr. Beltran commented education can always help to improve the program. Agree to review the cases? MB agreed
 - g. Charlotte Buchanan asked how many time critical results do you call out weekly on average. MB replied 5-10 weekly, but 80% are to NICU's with TPN contamination
 - h. Paul Harrison commented that we may change wording of testing not completed to rest of testing not completed.

13. Next Meeting Date

- i. **May 11, 2023 Virtual Meeting**
- ii.

Dr. Beltran made motion to adjourn; Gail Webster seconded