# KANSAS NEWBORN SCREENING ADVISORY COUNCIL MEETING

## ONLINE VIA ZOOM MEETING

# MINUTES

## MAY 12, 2022

**Members Present**

Emily Barr, Dr Jennifer Gannon, Dr Carolina Beltran, Julie Wellner, Dr Kourtney Bettinger, Dr. Brittan Zuccarelli, Shobana Kubendran, Dr Mike Lewis, Karey Padding

**Members Absent**

Dr. Thomas Loew

**KDHE Staff Present**

Michelle Black, Drew Duncan, Kinsey Anderson, Michelle Mills, Phillip Davis, Patrick Hopkins, Marilee Lowrey, Phil Adam, Connie Neuhofel, Shane Morris

**Others Present**

Charlotte Buchanan, Emily Stelle Gail Webster, Hannah Radke, Karen Braman, Kourtney Bettinger, Meghan Strenk, Dennis Dobson, Elisa Seeger, Ilana Chilton, Kirsten Finn, Paul Roesch, Rachel Love, Troy Reimer, Walid Maaty, Bryce Heese, Dawn Mercer.

**ACITON ITEMS**:

1. **Action items:**
    a. **Have HgB materials reviewed by families and council members.**
    b. **Have HbB materials available in more than one language – avail. in most common languages for populations most likely to be affected**

**Meeting Recording:**

*Link*: https://us02web.zoom.us/rec/share/JmowuhSUhm0Z_MzT7Wf9YyM7tH3Zq5xjOHJaBd-PcKyINKvTm6ZfcTJDHCEpqA9U.scIe038zylDWfWX0

*Access Passcode*: KSNBS2022!

**Minutes –**

1. **Housekeeping: 10:08 in meeting (5:26 on recording)**
    a. Minutes were sent out from last month and reviewed by committee members.
    b. Dr. Zuccarelli motioned to approve the minutes Dr. Bettinger seconded.
2. **Action items: 10:09 in meeting (6:27 on recording)**
    a. Have HgB materials reviewed by families and council members.
    b. Have HbB materials available in more than one language – avail. in most common languages for populations most likely to be affected
        i. New Plan (goal to start third quarter 2022)
            1. Adapt/condense CDC and MedlinePlus resource for KS/KDHE information documents
            2. Design and implement all materials simultaneously
            3. English/Spanish in print, QR codes for digital versions in additional languages.
3. **General Program Updates 10:12 in meeting (9:20 on recording)**
    a. **Legislative session -Regulations revisions –**
        i. SB 155 passed by the Senate, introduced and referred in the house
        ii. Regulations revisions progress.
            1. Investigating the possibility of charging for cards. (11:56 on the recording)
            2. Karen Brennan, KHA, wanted clarification on who would be charged, providers? Kinsey responded it would be collectors. Individuals that are ordering cards from KHEL would be charged for the cards. She stated that they are in support of fee based cards.
            3. Dr. Gannon stated that if KS were to charge for cards it would not be out of line with what other states are doing. She also addressed that it is a standard of care to screen within 24 -48 hours and it would be a breach of care to not screen because they didn't' want to pay for NBS cards.
            4. Julie Wellner asked if KHEL would be charging for PKU monitoring and Drew responded that decision has not be made but at this point the discussion is only for NBS cards.
            5. Michelle Mills stated that on the NewSTEPS website provides information on states that charge and where that funding goes. She also stated that KS is only one of 3 states that are not charging for NBS. Other states also provide PKU monitoring free of charge.
            6. Gail asked that they be a few months' notice if we are going to start paying for the cards. Kinsey replied that we have protocol to give 30 days' notice to any program changes, so yes providers would have notice so they could prepare for the change.
    b. **Data System Review 10:28 in meeting (25:03 on recording)**
        i. Problem identification phase is complete.
        ii. Moving into Solutioning phase
            1. Major findings. Need for better data system support/maintenance from hired or contracted system admins

2. Need for more technical/administrative support for both lab and follow up systems
3. Continue to increase and improve communication between lab and follow up, particularly with regard to strategic plans and process improvement (as opposed to the day to day granular work);
4. Improving the interface between our systems (particularly to reflect more real time data)
5. Lab – more automation within the system;
6. F/U – more automation/fewer "system inputs"; better match our actual workflows and task handoffs
7. Day to day support – low hanging immediate solutions, streamlining processes, data verification, and communication between programs
8. Vendor assessment
9. Potential funding streams to support operatios

**c. New/Continuing CQI- 10:35 in meeting (31:42 on recording)**

i. Facility Report Cards (Timeliness and Unsats)
ii. Internal Notification System
1. Working on a prototype and other options.

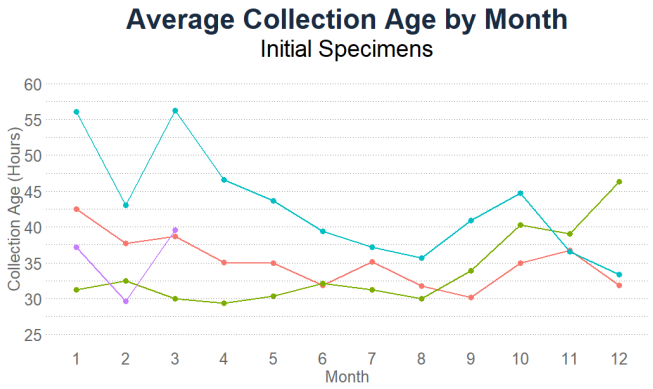
**d. Staffing Updates 10:38 in meeting (35:28 on recording)**

i. F/U Staffing
ii. Lab Staffing
1. Newborn Screening Staffing
a. COVID assist
b. Moved two temporary staff to full-time
2. Two full-time openings posted.
3. NBS Technical Supervisor promoted to COVID manager
a. Position held in case of return
b. Can assist with TS duties on an emergency basis, if needed
4. Covid 19 and Newborn Screening
a. Covid staff are now assisting in NBS daily
b. NBS staff who had previously been assiting in Covid are now in NBS.

**4. Data Discussion 10:53 in meeting (50:00 on recording)**

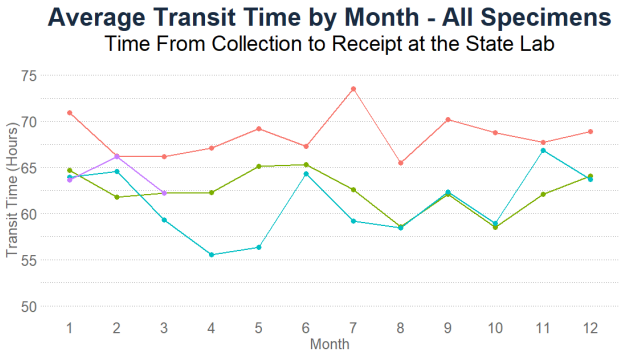
a. Collection Age:
i. Most notable fluctuations align with
1. Decrease in education activities in late 2020 and early 2021.
2. COVID-19 waves (by visual inspection)
ii. Early 2022, near return to pre-pandemic average.

iii.



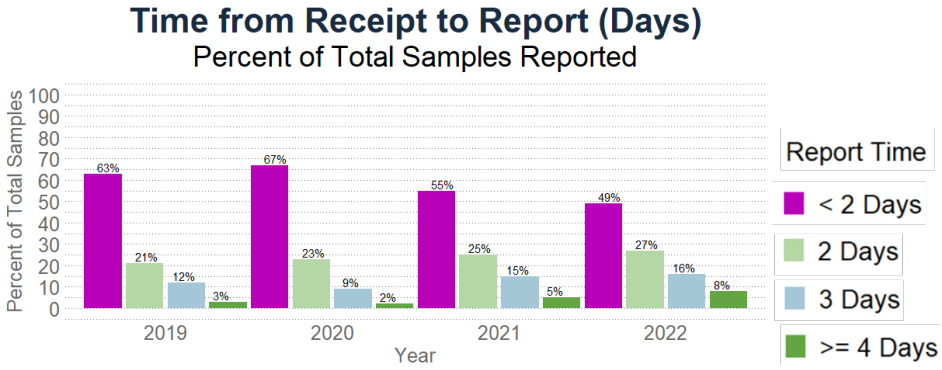

b. Transit Time.
   i. 2019- 68.6 Average hours. (2.9 days)
   ii. 2020 62.4 Average hours (2.6 days)
   iii. 2021 60.9 Average hours (2.5 days)
   iv. 2022 64.0 Average hours (2.7 days)
   v. Slight increase in 2021 due to addition of Lysosomal Storage Disorders.

vi.



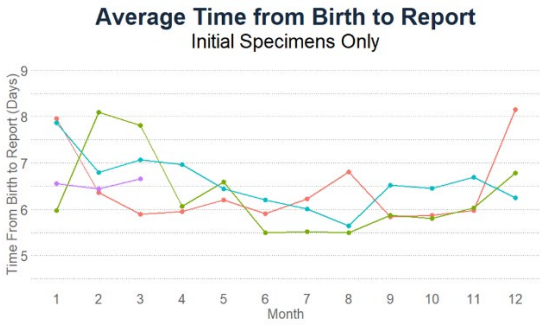

c. Time from Receipt to report
   i. 2019- 40.3 Average hours. (1.7 days)
   ii. 2020 38.3 Average hours (1.6 days)
   iii. 2021 44.2 Average hours (1.8 days)
   iv. 2022 46.9 Average hours (2.0 days)
   v.

vi.



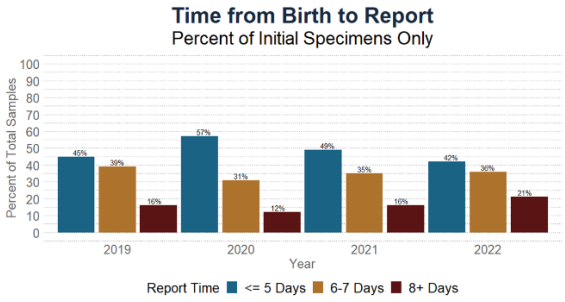

vii. Time from Birth to Report

1.




viii. Percent of Initial Specimens Reported in Given Timeframes

1.




ix. Difference by Collection Age

1. Birth to Report

| | | Initial Samples Collected ≤ 48 Hours | | | | | Initial Samples Collected > 48 Hours | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Total Initial Samples* | *Total ≤ 48h* | *% of Initial* | *Reported in 8+ days* | *% of Initial* | *% of ≤ 48h* | *Total > 48h* | *% of Initial* | *Reported in 8+ days* | *% of Initial* | *% of > 48h* |
| **2019** | 36,735 | 34,366 | 93.6% | 4698 | 12.8% | 13.7% | 2,369 | 6.4% | 1304 | 3.5% | 55.0% |
| **2020** | 35,977 | 33,939 | 94.3% | 3188 | 8.9% | 9.4% | 2,038 | 5.7% | 1186 | 3.3% | 58.2% |
| **2021** | 35,596 | 32,983 | 92.7% | 3887 | 10.9% | 11.8% | 2,613 | 7.3% | 1854 | 5.2% | 71.0% |
| **2022** | 8,775 | 8,355 | 95.2% | 1571 | 17.9% | 18.8% | 420 | 4.8% | 290 | 3.3% | 69.0% |

2. Receipt to Report

| | All Samples Collected ≤ 48 Hours | All Samples Collected > 48 Hours |
|---|---|---|
| **2019** | 40.0 Hours (1.7 Days) | 42.0 Hours (1.7 Days) |
| **2020** | 38.1 Hours (1.6 Days) | 39.1 Hours (1.6 Days) |
| **2021** | 43.8 Hours (1.8 Days) | 46.0 Hours (1.9 Days) |
| **2022** | 46.6 Hours (1.9 Days) | 48.3 Hours (2.0 Days) |

3. Discussion on timeline and batching. KHA said they would be able to help do education on timeliness and batching.

x. High Risk Screen Positive and Positive Predictive Value. (Chart can be seen on PowerPoint) **(1:08:26 on the recording)**
    1. Dr. Zuccarelli asked about a small sub committee that tracked demographics of specific conditions. She stated that she just prays that these babies are getting the care that each baby needs.
    2. Kinsey answered the question that adding a zip code is not as accessible as it could be. Our data system is not set up for this information.
    3. Per Drew we are collaborating with other agencies to ensure babies are receiving the care they need. Per Kinsey we are working with DCF to ensure the follow up of cases in foster care.

**xi.** Unsatisfactory Specimens **(1:38:46 on the recording)**
    1. Three different graphs in the power point.
    2. 2020 had a decrease in unsats. 2021 the rates of unsats did trend up.
    3. Although trends on Unsat did go up but are starting to come back down.
    4. Reviewed a chart of the unsat code trends.
    5. Michelle Mills explained how the lab determines an unsat spot and the need for more complete spots especially if the specimen needs 2nd tier testing. Disclosed that there was a training error in reading unsats and addressed if there was more then one unsat code to list them all. Michelle explained why blood on the coverlet is a concern when the blood is transferred to the coverlet and then not in spot.

**5. KHEL Updates – 11:58 in meeting (1:55:02 on the recording)**

**a.** Sunday Courier – chart can be viewed on the power point. Plans to keep going after grant ends (3 years) – which will be next Summer

**b.** LabOnline – KA talked about actively recruiting submitting facilities to sign up to see lab reports – able to add letters and other reports, looking at submitting facilities being able to look at those as well

**c.** LabExchange – electronic submission and collection of data – KA will be seeing demo tomorrow-discussions of piloting and roll out. Phil – cut down on faxing facilities for additional information. KA – also hope to reduce human errors due to data entry – Meghan Strenk – good for them to sign up at CMH? – KA – No, b/c they are not the submitting facility, but hopefully will later

**6.** 12:09 Break until 12:25

7. **New Conditions – RUSP and KS Priorities 12:25 in meeting (2:24:14 on recording)** –

**a.** MM talked about NBSTRN as another resource – MPSII, GAMT, CMV; now some states are adding more than one per year and could be for next 10 years; how do we prioritize?
    i. Courtney Bettinger – create rubric, potential benefit of an area for a screen
    ii. Jen Gannon – needs to be cost effective, how good of a test is it, how specific/sensitive is test, do we have the equipment, what is the incidence in our state – extensive expert review to be on RUSP – there are limited resources. Agrees helpful to come up with rubric
    iii. KA – maybe a weighted scored system of a rubric

iv. Jen Gannon – MO example, is not screening NMen PIC AB b/c there is no treatment
v. MM – CMV issue is that the incidence rate is 1 in 100, so huge burden on f/u team. Can implement easily in lab, but impact on f/u would be big – as an example of things to look at
vi. Moved on with no conclusion or decision made

**8. Follow Up Updates – 12:38 in meeting (2:35:25 on recording)**

a. Dr. Bettinger started as Medical Director last month
b. KA – Specialist Contracts; Genetic and Metabolic conditions have the largest amount of cases. each subspecialty contact will need to be unique. Will move on to Referral Model. Propose to move on with CMH and Wesley and have more detailed conversations for Genetics and Metabolics
c. Mike Lewis – Any states experience w/contract 1 person for Augusta, KS – they are ill and take leave – trying to keep pts in their community, but healthcare systems that don't play nicely have to. pediatric specialty medicine is under represented; have referral of how another smaller community does these
d. KA – these are Referral center models that are consultation support to PCP's, but cannot have a contract w/every single provider
e. Dr. Zuccarelli – SMA 2 on year per average; doesn't need a contract, but give list of 4 people and let them choose; KA agreed
f. Jen Gannon – clarify don't want referral center model; what they do is give free advice to PCP's, and cannot bill for unbillable services, so that is why to have contracts; KA-grey area that PCP will consult with Specialist with whom they are planning to refer family to. In MO, much more geographically based. Jen-they are not asking for a double dip, but for the amount of unpaid time
g. Drew – not a perfect solution, but a start
h. Shobana asked what time line was for starting discussions. KA replied June

**9. Education Updates – 12:58:20 in meeting (2:54:43 on recording)**

a. Facility outreach –- creating outreach plan from scratch
b. Outreach Materials – finalized Guide to KS Family Supports; working on translations – finished Health Equity Training Course, so has new tools to use to cover all aspects of health equity
c. Website updates – continue and are slow; done in small bits, will be changing location of pages KA – there are short term and long term plans to continue to update, short term moving pages; long term Vanity website, more user friendly (MN and TX have been good examples)
d. Online training – decrease in number of people attending during COVID, but numbers are slowly coming back up
e. Newsletter updates – in last year upward trend in people opening newsletter; will start using MailChimp to track
f. 2021 Facility Recognitions – awards event in person w/virtual option. Asking for success stories (facility and families). Next year will have option to send in photos for the following year's cover. Time and place have not yet been decided.
g. Family Support Pamphlet updates

i. Distribution locations
    1. Dept of Commerce – workforce center
    2. DCF – field offices
    3. Local health depts.

**10. Comment or discussions – 13:13 in meeting (3:11:56 on recording)**

a. None

**11. New Business – 13:16 in meeting (3:12:49 on recording)**

a. Karey Padding – Gavin, her son, has CF. Through the CF Foundation there is a Steering Committee for NBS. The goal is to improve timeliness, equity, and sensitivity in diagnosing CF through state quality improvement indicatives. Will have 2 subcommittees, she has been assigned to the Timeliness sub-committee made up of CF clinicians, PCP, genetic counselor, State lab directors and 3 parents.

12. **Next meeting** is scheduled for Sept. 15, 2022, in person in Topeka w/virtual option
13. **Adjournment** – Kourtney Bettinger moved to adjourn; Karey Padding seconded
**14. Adjourned at 1:21**