

**KANSAS NEWBORN SCREENING ADVISORY COUNCIL MEETING**  
**ONLINE VIA ZOOM MEETING AND IN PERSON IN KAMMCO**  
**MINUTES**  
**AUGUST 31, 2023**

**Members Present**

Carolina Beltran, Dr Kourtney Bettinger, Dr. Mike Lewis, Karey Padding, Meghan Strenk, Dr. Britton Zuccarelli, Julie Wellner, Gail Webster, Karen Braman

**Members Absent**

Emily Barr, Dr. Grace Brouillette, Dr. Laurie Gwyn, Dr. Thomas Loew, Dr. Jennifer Gannon, Dr. Selina Gierer, Shobana Kubendran, Michelle Leeker, Karen Brahman

**KDHE Staff Present**

Michelle Black, Drew Duncan, Michelle Mills, Marilee Lowrey, Connie Neuhofel, Shane Morris, Karla Morcado Morales, Austin Weaver, Elizabeth Schardine, Zac Leeker, Hanna Radke, Abegail Bauer, Timothy Kim, Mercedes Robinson, Sally Brownlee, Tyler Brinlee, Alex Keyes

**Others Present**

Charlotte Buchanan, Monica Davis, Dr. Andrea Dmello

**ACITON ITEMS:**

From January meeting: Dr. Beltran asked that we continue the conversation about possible in person event to hand out annual awards.

From today's meeting.

1. Dr. Beltran requested an update on CF.
2. Review how it worked to have a 6 month period for meetings and take a vote as to the frequency of advisory council meetings.

**Minutes** – Dr. Bettinger moved to approve and Kari Padding seconded.

**1. General Updates-**

- i. Data System Update
  1. RFP for new data system

2. KITO/CITO approval process
- ii. Legislative Updates
  1. Conferences – APHL Conference
- iii. Staffing Updates
  1. F/U Staff -
  2. Lab Staffing -
- iv. HRSA NBS Propel Grant -
  1. KS was awarded a 5 year grant to expand NBS capacity and establish long term follow up capabilities.
  2. Shared grand award between follow up and KHEL
  3. Start date July 1, 2023.

Year 1	Year 2
<ul style="list-style-type: none"><li>• Purchase new diagnostic instrument</li><li>• Transition Biotinidase and GALT to new instrument</li><li>• Implement and validate new instrument</li><li>• Follow up data system enhancement</li><li>• Hire long term follow up position</li><li>• Hire Contracted Genetic Counsellor Position</li><li>• Development of long term follow up processes</li></ul>	<ul style="list-style-type: none"><li>• Evaluate any RUSP conditions not currently screened for</li><li>• Evaluate conditions that can feasibly be brought on</li><li>• Lab onboarding of any new conditions</li><li>• Letters and fact sheets created for any new conditions</li><li>• Purchase of 2 new plate readers</li></ul>

1.
  4. Dr. Beltran wanted to know if there would be discussion of how the grant money will be spent and an opportunity for others to give feedback.
  5. Drew stated that the long term follow-up coordinator position has been approved. There is also money in the grant for a part time genetic counselor.
  6. Julie is asking if we will look at other states that have genetic counselors to see how they utilize their services for NBS.
    1. Kari Padding -Do those other states have long term follow up as well. Some do but others do not and the definition of LTF is different for each state. Some states focus
- v. Break Ground for New Lab – Projected opening date of June 2025. Instruments will be moved.
2. **Staffing-**
  - i. KHEL
    1. New Laboratory Director Dr. Sameer Sakallah, June 12, 2023
  - ii. NBS Follow Up
    1. New Program Program Manager, Zac Leeker April 2023
3. **Condition Discussion**
  - i. HgB Trait Discussion

1. Misconceptions surrounding trait and “no negative health impacts’.
  1. F/U is assessing the recommendations for trait.
2. Current guidance to wait 9-12 months to repeat is causing loss to follow up. Is this necessary?
  1. Marilee clarified that we recommend electrophoresis at 9-12 months.
3. Dr. Lewis commented that his experience is that baby’s are getting electrophoresis at 3-4 months.
4. Julie questioned if we had an hematologist on our council. Dr. Bettinger asked if Dr. Loew was present today and he was not.
5. Drew stated that Dr. Sherney provided her documents for our program to utilize.

ii. SCID Discussion

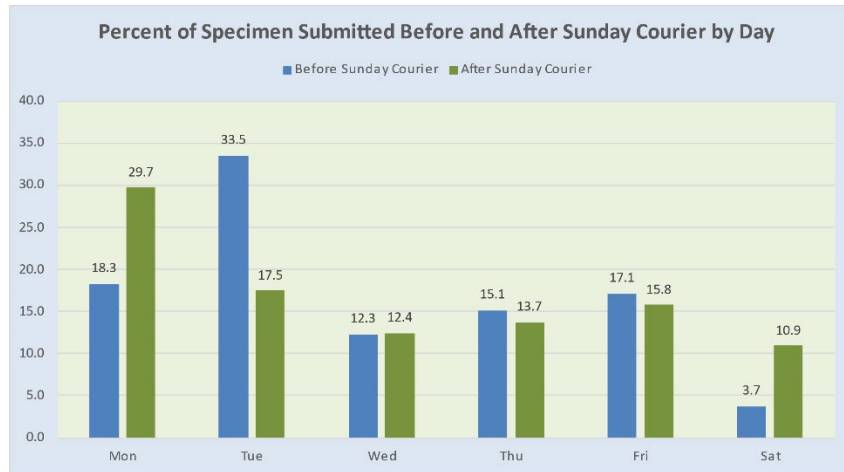
1. Rephrasing to “Low T-Cell Count” rather than SCID specifically
2. Program recommendation: Removing ‘cease breastfeeding’ recommendation for Low Risk SCID. -Repeat-
3. Gail asked when this uptake started. March of 2023. Then asked if other states are seeing in uptick also. There is a seasonal uptick but not at the level we are seeing it in Kansas.
4. Drew asked for Zac to share what other states are seeing.
5. Dr. Dmello shared what she found online in the chat.
  1. She stated that if the screen is reported out at 5 days of age then baby has already been exposed to mom’s breastmilk and stopping breastmilk and harder on the infant.
  2. Gail commented that CMV infection is much more likely from placenta then breastmilk.
  3. Dr. Dmello commented in the chat about what she had found online.
6. Dr. Bettinger moved to remove the recommendation for breastfeeding while waiting for a repeat screen. Gail seconded. Clarified it was for low risk repeat NBS only.
7. Dr. Bettinger asked if we asked parents if they understood what Low t cell meant during our focus groups and we did not.
8. Gail asked if parents are told about a condition. Staff responded with parents are given a letter to ask for a repeat.

4. **KHEL Update**

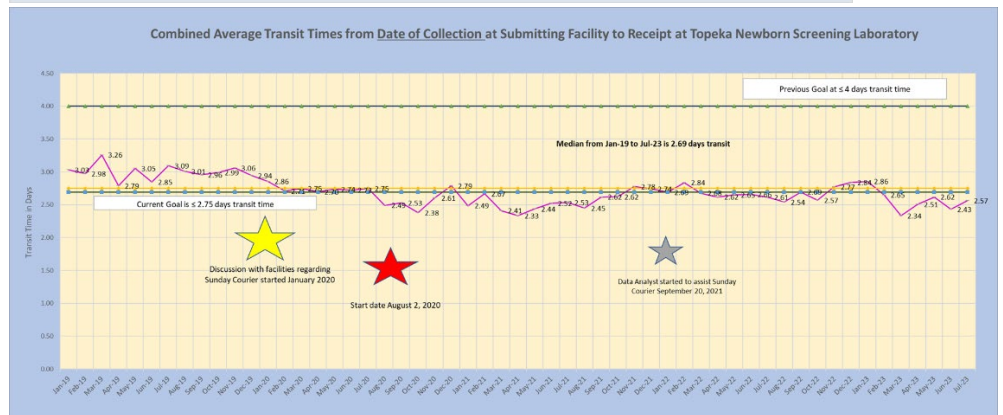
- i. Update on new conditions
  1. X-Linked Adrenoleukodystrophy
    1. Validation complete
    2. Pre-Pilot complete

3. Piloting in progress
  - a. Four reported as borderline/low risk to follow up
    - i. Three had normal subsequent specimens
    - ii. One pending
  - b. One reported as high risk to follow up.
4. Go Live
  - a. Estimated go live end of 1<sup>st</sup> quarter 2024
2. Mucopolysaccharidosis II
  1. Validation complete
  2. Pre-pilot in progress
3. Recommended Uniform Screening Panel
  1. The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) met August 9-10, 2023
    - a. *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.
    - b. *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.
    - c. *Krabbe* was unanimously voted to move forward for expedited evidence review for consideration for RUSP inclusion status on August 10, 2023.
    - d. *Duchenne's Muscular Dystrophy* was voted to move forward to full evidence review on August 9, 2023.
  2. Next ACHDNC meeting is November 2-3, 2023.
4. APHL Quality Improvement Grant ended July 30, 2023.
  1. State of Kansas received approximately \$450,000 in the last 4 years
  2. Aim of the QI grant was to improve transit time to  $\leq 4$  days from collection to receipt for those facilities in KS which submit the most specimens
  3. Aim was achieved as transit time improved to  $\leq 2.75$  days from collection to receipt for those participating in the Sunday Courier service
  4. Median transit time from collection to receipt since Sunday Courier started is 2.62 days
  5. Median transit time from collection to receipt in 2023 is 2.57 days

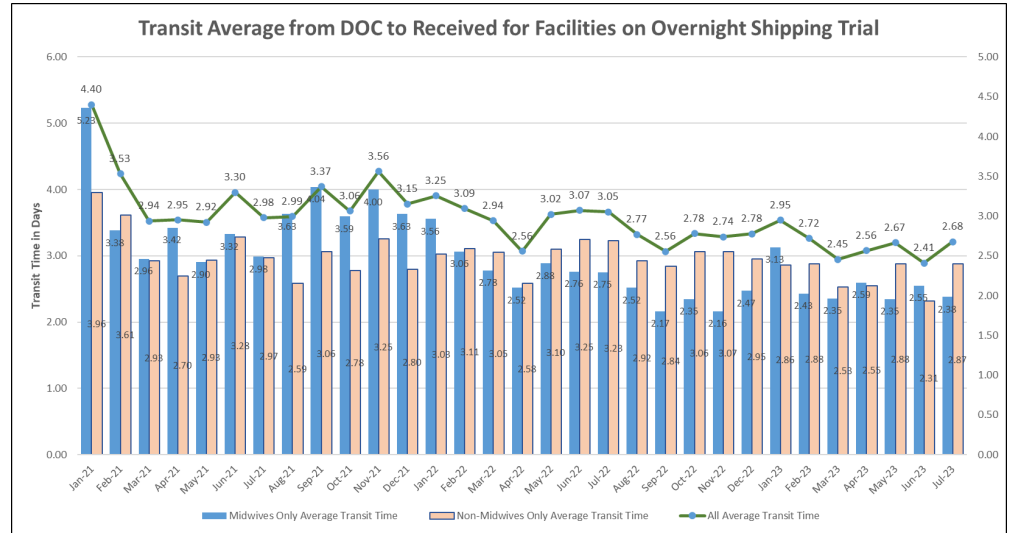
6. Approximately 30% of all specimens are now received 24 hours sooner since Sunday Courier was implemented
  7. Birth to report turnaround time improved approximately 20% since adding Sunday Courier according to our data analyst
  8. Governor had a 3<sup>rd</sup> party evaluate the need for Sunday Courier, and recommended it continue as part of the Kansas NBS Program
5. Sunday Courier Grant



1.

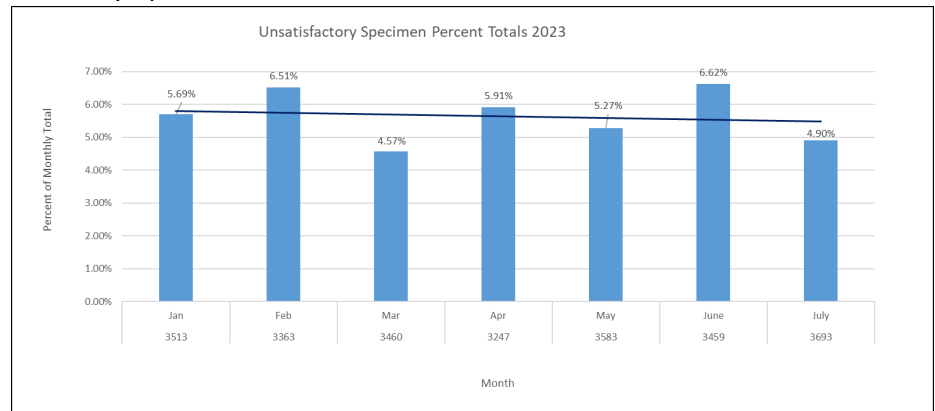


2.



3.

## 6. Unsatisfactory Specimens



1.

## 7. Follow-Up Updates

1. Consultation Contracts – Final Stage of Review
2. Medical Director Updates
3. Comprehensive Letter Review
4. Completed family focus groups
  - a. Provider interviews
  - b. New letters drafted based on feedback
  - c. Invalid HGBs
  - d. Infant without a screen

## 5. Comprehensive Letter Review

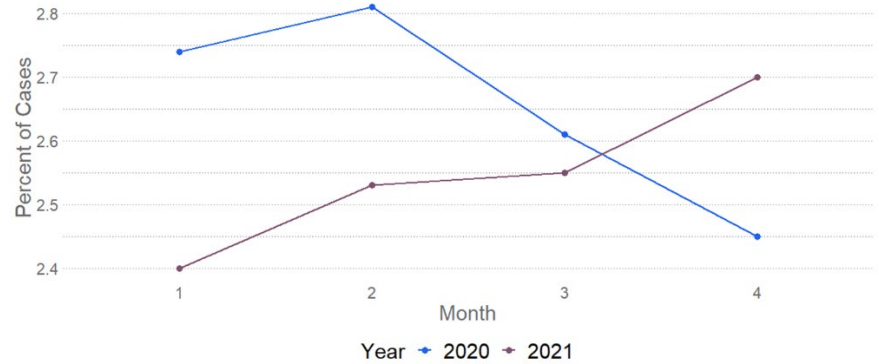
- a. Internal Review then Stakeholder Input then Implement changes.
- b. Parent Documents
  - i. Parent letter
  - ii. Disorder information sheets for families

1. Revised for health literacy accessibility, clarity, situational and condition information.
  - iii. Internal review is complete, and the next step is to get parent feedback. Then will be sent to communications department for approval.
  - c. Provider documents
    - i. PCP letter
    - ii. Disorder report forms
    - iii. Disorder information sheets for Providers.
    - iv. ACT sheet
    - v. Algorithms
      1. Re-evaluated within a larger context of program's protocol of communicating abnormal results as how we communicate dictates what kind of documents we create.
6. Unresolved Cases by Quarter

**Percent of All Cases that are Unresolved by Quarter**

2020 Percent Unresolved - 2.65%

2021 Percent Unresolved - 2.55%

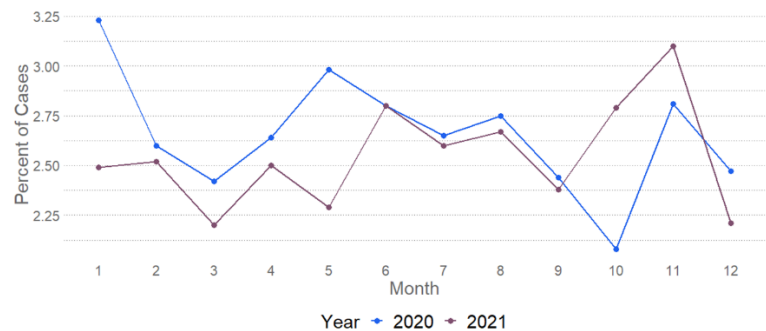


- a.
7. Unresolved cases by Month

**Percent of All Cases that are Unresolved by Month**

2020 Percent Unresolved - 2.65%

2021 Percent Unresolved - 2.55%



a.

8. Hearing and WebIZ updates –

1. Late onset hearing loss

- a. The state hearing program has joined the LOHL awareness campaign.
- b. Standard newborn hearing screenings do not identify all children who are d/hh due to missed mild losses, delayed onset hearing losses, progressive hearing losses, or genetic hearing losses.
- c. The CDC estimates that nearly 15% of children ages 6-18 years of age have some level of permanent hearing loss.
- d. While newborn hearing screening data is reported and tracked each year, children who develop hearing loss after birth often go unnoticed, undiagnosed and untreated - leading to speech, language, cognitive and developmental delays and social/emotional problems.
- e. Hearing loss doubles from newborn 3/1000 to 6/1000 once a child reaches school age.
- f. The goal of this campaign is to raise community awareness so that families, childcare providers, preschools, pediatricians and others who observe or suspect missed developmental milestones in early childhood will ask the question, “Could this be linked to hearing loss?”

2. Kansas WebIZ

- a. Memorandum of Agreement
- b. Read Only Access
- c. Lost to Follow Up
- d. Verify Current Address
- e. Primary Care Provider
  - i. Partnering with Kansas Web Immunization program to help reduce the number of infants who do not complete the screening process or necessary rescreens and follow up.
  - ii. We know that babies should receive their first vaccinations 1-2 months after birth and then every couple months after that.
  - iii. Often times the PCP, address or telephone numbers are not valid that are given for the birth certificate.
  - iv. We will have view only access which will allow the programs to view the most current demographics,



primary care physician or facilities they are attending.

## **9. Hearing and CCHD Updates**

1. Late onset hearing loss campaign.
  - a. Hearing loss can occur at any time as a result of:
    - i. Illness
    - ii. Physical Trauma
    - iii. Environmental factors
    - iv. Genetic factors
  - b. The CDC estimates that nearly 15% of students age 6-19 have significant hearing loss.
  - c. Prevalence rate doubles 3-1000 at birth 6-1000 by kindergarten.
  - d. Potential Partners in Early Identification of Late Onset Hearing Loss
    - i. Kansas EHDl Goal
      1. Continued OAE trainings and support
      2. LOHL brochure and disperse to stakeholders
      3. Share information at conferences
      4. Present at Stakeholder conferences
      5. Educate physicians
      6. Educate Child Care Facilities
      7. Educate Schools and Nurses
      8. Collect hearing loss diagnosis on all children 0-8 years of age
      9. State repository for all 0-8 years of age with hearing loss
  - e. Regulations
    - i. CCHD Follow Up
      1. Daily OVS import
      2. Confirm not screened
      3. Request EHCO reports
      4. Make referrals

## **10. Education and Outreach Updates**

1. Outreach Activities
  - a. Increasing visits to hospitals, clinics and labs in 2023.
  - b. Increased presence at community health fairs and other cross-cutting events.
    - i. Baby Showers
    - ii. Housing Conference

- iii. GPHC
- iv. NEK Head Start Conf
- 2. Guide to Kansas Family Support
  - a. Hospital and Birthing Centers
  - b. More than 5,000 pamphlets have been disseminated to various hospitals and birthing centers.
  - c. On schedule to deliver to all Kansas birthing centers by year end.
  - d. Education to introduce brochure during the prenatal period.
  - e. Additional Resource Locations
    - i. Over 24,000 pamphlets have been distributed to non-birthing locations.
    - ii. Average of 25 to 100 pamphlets per location, some of which include
  - f. Public Libraries
  - g. Workforce Centers
  - h. Childcare Centers
  - i. Non-profits
  - j. Health Depts.
  - k. DCF
  - l. Goodwill
  - m. Housing Authority locations/clinics
- 3. Newsletter Numbers and Updates
  - a. Average Open rate of 36% for all of 2022
  - b. Open rate up by 1.2% from 2021
  - c. Total of 281 subscribers
  - d. Open rate for June and July of 2023 at 40%
- 4. Additional Activities
  - a. Vanity Website for Screening & Surveillance is in final phases (expected launch in 4th quarter of 2023)
  - b. Increased focus on building out library of digital content
    - i. Exploring potential for YouTube channel
    - ii. Training Videos
    - iii. Short Clips for Frequently Asked Questions
    - iv. Uploading Monthly Webinars
  - c. Interactive map for outreach tracking – working on tracking on a map where outreach efforts are happening
  - d. Newborn Screening Brochure Updates
    - i. Will include translation into multiple languages

ii. Double sided (English/Spanish)

11. Comments/Discussion –

1. Dr. Beltran would like to discuss potential new conditions.
  - a. Wanted clarification on how the lab is testing X-Linked.
  - b. Michelle Mills stated we have not seen any issues
    - i. Michelle Black stated we are following up on the 2 high risk and both are pending DNA testing.
  - c. Dr. Beltran was asking if DMD was talked about during our last meeting. It was not but on a federal level it is being discussed to be added to the RSUP.

12. New Business –

- a. Dr. Beltran requested an **action item** to update for CF?
- b. Dr. Lewis stated that KS should be proud because we are way beyond what other states are doing in terms of CFTR
2. Gail asked about being able to complete the bloodspot card online. It is available and Michelle Black can forward her the registration form.
3. Dr. Zucerelli – asked if we have had any SMA this year. She was reassured we have not had any flag this year. MM stated that we should find 2 each year and we have not had any flag in 2023.
4. Zac brought it to the council that we would like to move back to twice a year meetings.
  - a. Dr. Beltran would like everyone involved to be able to comment. (I am not sure I got this right)
  - b. Dr. Beltran appreciated 3 meetings a year to keep everyone in the loop of what is happening.
  - c. Drew stated that going to twice a year gives staff more capacity to focus on other things. Capacity is limited and we are focused on bringing on a new data system. We are also focused on meeting the grant steps and documentations.
  - d. Dr. Beltran asked for others comments and to take it to a vote.
  - e. Shane Morris stated that there will be news and events along with a blog post online to keep people engaged.
  - f. Karri Padding asked if capacity would grow with the addition of a long term follow up person. Drew responded that yes it will grow with a new position and the implementation of a new data system.

- g. Dr. Beltran stated that having meetings is more personal and gives the council an opportunity to have discussions on a regular basis. She also requested starting meetings at 10:00 again. She is also concerned that we have so many new conditions being brought on and we need to continue to meet 3 times a year. She doesn't feel that emailing information is as beneficial.
  - h. Charlotte Buchanan stated that getting comments and discussions may be difficult with only 2 meetings a year.
  - i. Gail suggested having the next meeting in 6 months and see if the communication was sufficient. **Action item** review meeting frequency and putting it to a vote in 6 months about the frequency of the meetings.
5. Drew commented that the next legislative session we will need support from members to educate legislative members about the need for funding.
13. Kari Padding has moved to adjourn the meeting and Gail seconded.
14. Next Meeting Date
- 1. March 1<sup>st</sup>, 2023 \*Tennatively Should be the Thursday.