

KANSAS NEWBORN SCREENING ADVISORY COUNCIL MEETING

ONLINE VIA ZOOM MEETING

MINUTES

SEPTEMBER 23, 2021

Members Present

Emily Barr, Dr Jennifer Gannon, Dr Carolina Beltran, Dr Grace Brouillette, Julie Wellner, Dr Kourtney Bettinger, Dr Merlin Butler, Dr. Laurie Gwyn, Michelle Leeker, Dr. Brittan Zuccarelli, Natalie Sollo, Patrick Hopkins, Shobana Kubendran, Dr Mike Lewis, Karey Padding

Members Absent

Dr. Susan Pence, Dr. Selina Gierer, Dr. Thomas Loew, Jessica Vail,

KDHE Staff Present

Michelle Black, Drew Duncan, Heather Smith, Kinsey Anderson, Casey Guccione, Michelle Mills, Phillip Davis, Rupinder Kaur, Patrick Hopkins, Marilee Lowrey, Phil Adam, Bishnu Adhikari, Erica Wade, Carissa Robertson, Connie Neuhofel, Shane Morris, Melanie Kessler-Mathieu

Others Present

Randi Gadea, Dr. Bryce Heese, Hari Patel, Dr. Grace Brouillette, Charlotte Buchanan

ACITON ITEMS:

1. Create document of definition / codebook
 - a. *DUE: January 20, 2022*
2. Add numbers of DBS to Data Information
 - a. *DUE: January 20, 2022*
3. Update the Advisory Council member list, schedule, and log-on information to the website
 - a. *DUE: January 1, 2022*

Meeting Recording:

Link:

Access Passcode: KSNBSAC52020!

Minutes

1. Housekeeping
 - a. Attendees answered icebreaker question in the chat
 - b. Approval of previous minutes (with no edits): Dr. Lewis moved to approved and Dr. Bettinger seconded.
2. Review of action items
 - a. Committee to send feedback and questions about adding a breastfeeding question to the NBS
 - i. *DUE: May 31, 2021 – Feedback rcv'd*
 - b. Committee to send feedback on new format of data discussion (data presented with context of program activities). Is this better or too much information? Any changes to the format that you would like to see?
 - i. *DUE: May 31, 2021 – Feedback rcv'd*
 - c. Committee to review and provide feedback on new Invalid Specimen Parent Letter
 - i. *DUE: June 1, 2021 – Feedback rcv'd, in translation process*
 - d. Committee to respond with any suggestions for the new website
 - i. *Due: June 30, 2021 – No Feedback rcv'd*
 - e. Kinsey to add question about meeting format (in person, hybrid, virtual) to next AC survey
 - i. *Due: July 23, 2021 – N/A as we have gone back to Telecommuting*
3. Follow Up Updates
 - a. Legislation/Regulations
 - i. Beginning of process
 - ii. Will be a long process
 - b. Breastfeeding and NBS
 - i. Conversation ongoing
 - c. Staffing
 - i. Screening and Surveillance Support Specialist
 - ii. Screening and Surveillance Admin Asst
 1. Roles are to Support NBS, POS, Birth Defects
 - iii. KHEL
 1. 2 Temps to fill open positions
 2. 3rd Temp will be added
 3. Vishnu, new KHEL on line employee
 4. Carissa Robertson – KHEL Quality Insurance Officer
4. Data Discussion
 - a. Feedback rcv'd - Review timeliness at every meeting
 - b. Collection Age
 - c. Transit Time
 - i. Days and Hours
 - ii. Decrease in 2020 due to Courier Project
 - iii. Increase from late 2020 to early 2021 due to Education position transition
 - iv. Decrease in March 2021 due to adding FedEx shipping labels to Courier Project
 - v. Increase due to staffing difficulties at facilities – possible COVID impact

- d. Time from Receipt to Report
 - i. 2019 decrease due to lab's protocol change, same day for flagged specimens (re-screen to confirm), used to be confirmed the next day
 - ii. Have seasonal impacts in winter due to shipment delays
 - iii. 2021 higher due to addition of LSD's
 - iv. Still reporting w/in national goals
 - v. Jen Gannon asked target time from birth to report – KA national goals for time critical report w/in 5 days, all results reported w/in 7
 - e. Average Time of Birth to Report
 - i. Collected 48 hrs or less after birth
 - ii. Consistently most specimens have had lab reports w/in 7 days, actually most w/in 5 days
 - iii. Changes in 2021 due to increased collection delays and transit delays
 - iv. Collected after 48 hrs after birth
 - 1. Typically not reported w/in 7 days
 - 2. Has impact on ability to get reports done
 - 3. Shane Morris – will avg time go up again when we add X-ALD? KA – no, b/c not doing 2nd tier testing
 - 4. Merlin Butler – how many DBS does 75% include? Small numbers or big numbers?
 - f. **ACTION: Committee feedback data presentation format is that definitions are needed of terms (Target Time, False Positive, LRN, etc.) and percentages need numbers to be relevant**
 - i. **Document of Definitions / Codebook**
 - ii. **Add numbers of what percentages represent**
 - g. Lost to Follow Up – Drew Duncan
 - i. Hearing Data – identify ways to impact socio-economic populations
 - ii. Can do a better job of connecting with these populations – created association with Grace Med
 - iii. Jen – Did we look to other states to get insights on how to address these findings? Drew-organic process, no-have not communicated with state partners, internally-know Medicaid is a big factor
 - iv. Jen – look at differences between urban and rural areas? Drew-different regions were significant, but didn't mean if you live there you were more likely to fall under LTF
5. Follow Up Updates
- a. What Data F/U Collects/Tracks
 - i. Jen Gannon – track False Negatives? KA – Education opportunity; Jen-not educate PCP's; KA-further discussion in another sub-committee
 - ii. Shobana – track time to find right PCP? KA-Not tracking; MB & ML confirmed they attempt to use all resources to find PCP before calling them
 - b. Proposed New Dx Forms
 - i. Discussed in X-ALD sub-committee
 - ii. Need more detailed info from PCP's for NewSteps

- iii. Update all forms for each condition to more closely follow and format that we report to NewSteps
 - iv. Definition of Time to Medical Intervention
 - 1. Randi Gadea – wouldn't it always be when baby referred to Specialist? – KA – not always – stop breastfeeding, etc; Randi-clarified talking about LSD's and X-ALD's where referring to Specialist is the first step; KA-yes
 - c. Referral to Other Services/Supports
 - i. Improved/updated letter
 - ii. Improving entire process of referring to Part C providers/SHCN and turning into
 - 1. Drew – Good quality improvement project to bring additional support to families
 - d. Contracts Progress
 - i. Medical Director and Specialist Consultants – will be moving forward; Jen Gannon-make sure they are consulted-data collection is different than “What do you think about what we want to do?” – Heather-if we make changes, consultation will be made before we do anything. Will contact families too.
6. KHEL Updates
 - a. COVID-19 and NBS
 - i. Staff turnover
 - ii. Staff assisting with COVID
 - iii. COVID staff assisting with NBS have been pulled back to COVID
 - b. Sunday Courier Grant
 - i. Successful addition to program
 - ii. Granted for another year
 - iii. Meeting goal of 2.75 days
 - iv. Want to get Date of Birth to Reporting TAT down
 - c. X-ALD
 - i. Showed pictured of Mass Spec instruments – installed
 - ii. Will move forward with training
7. Education Updates
 - a. Facility Recognitions for 2020 are now completed.
 - b. New categories: Most Improved.
 - c. Point of Care
 - i. Hearing Screens Completed within 1 month, Hearing screening referral Rate. Percent of CCHD Screen reported.
 - ii. Metabolic:
 - 1. Unsat specimen percent, average collection age, average transit time.
 - d. What to do with blank pages or dead space?
 - e. Website Updates Phase II
 - i. Completed review
 - ii. Phase II will focus on content development
 - iii. If you have suggestions on content for our weblinks, please submit them to shane.morris@ks.gov

- f. Newsletter Stats
 - i. We anticipate the creation of a newsletter quarterly, but we have been able to do one every month since January
 - ii. Some of the basic statistics of the newsletter are as follows:
 1. Audience = 299 subscribers
 2. 62 - Hearing Coordinators
 3. 25 - Midwives
 4. 19 - KDHE staff
 5. 15 - FAC members
 6. 15 - NBS AC Member

g.

	Newsletter	Calendar	Email	Webinar Name
Total Registrations	33	12	20	Blood Spot Collection Technique
Total Registrations	18	2	12	NBS Basics and Metabolic Review
Total Visitors (clicks)	2173	12	24	Blood Spot Collection Technique
Total Visitors (clicks)	64	2	16	NBS Basics and Metabolic Review

- h. New combo brochure
 - i. First draft received high approval from Education & Outreach Committee
 - ii. Of the color options, green was preferred color for cover
 - iii. Official title is still in development
 - iv. QR Codes work properly
 - v. Room for additional Prenatal Program
- i. X-ALD Brochure
 - i. First draft of the X-ALD Info Brief for Families and Providers completed
 - ii. Used same format as LSD briefs
- j. New outreach opportunities
 - i. Prairie Band Potawatomi Nation Health Clinic
 - ii. KDHE funded providers (20 total providers):
 1. Teen Pregnancy Targeted Case Management (TPTCM) Program
 2. Pregnancy Maintenance Initiative (PMI)
 - iii. Partnered with Children & Families Unit to collaborate on outreach materials
- k. Dr. Phil informed the committee that Lab exchange will be ready in 3 -4 weeks.
 - i. Idea will be that hospitals can submit the demographic information electronically.

8. Subcommittee Updates

- a. Metabolic
 - i. Lab continues to collect data to determine utility of a new ratio to better identify babies at risk for VLCAD
 1. C14:1/C16-OH ratio for carriers vs. diagnosed infants

- ii. FYI - Guanidinoacetate methyltransferase (GAMT) deficiency
 - 1. In discussions to be added to the RUSP
 - 2. Could be added to KS panel without much laboratory effort
 - 3. Incidence is low at 1/250,000 in KS
- iii. Committee will continue to meet every three months, as needed
- b. X-ALD
 - 1. Follow Up progress:
 - 1. PCP "Next Steps" clarified
 - 2. Follow Up Letter/Fax drafts for pilot completed & reviewed
 - 3. Diagnostic Reporting Form completed & reviewed
 - 4. ACT sheet and Physician Info sheet drafts in committee review currently
 - 5. Pilot tracking sheet for Case Management prepared
 - ii. Education and Communications progress:
 - 1. Info Sheet for Families in committee review currently
 - 2. Info Brief for Physicians in progress
 - 3. Communications materials in progress (social media, announcement letter, press release, etc.)
 - iii. Laboratory progress:
 - 1. Building modifications made
 - 2. MS Equipment installed
- c. LSD Subcommittee
 - i. Specimens analyzed, approx. 30,000

	Diagnosis Confirmed	False Positive	Pending Diagnosis
GAA	2	1	1
IDUA	0	0	2
Total	2	1	3

- ii. Using Two Types of 2nd tier screening is very beneficial!
- iii. Updated follow up protocol to recommend *consultation* with a specialist for next steps in cases where an infant has had two or more borderline screening results
 - 1. Laboratory protocol did not change - if results are borderline, the report will say borderline regardless of number of previous borderline results for LSDs
- iv. Due to global shortages in supplies, our vendor for second tier genetic screening has changed their protocol to send specimens to a third party
 - 1. Our contract for this service is still with Baebies, Inc. and they are still fulfilling the contract to complete second tier screens
 - 2. Change has caused temporary delay in genetic screening results as the change is implemented

3. Once resolved, turn around time will be similar to original turn around time
9. Comment or discussions
 - a. No comments or discussions
10. New Business
 - a. None
11. Next meeting is scheduled for Jan. 20, 2022.
12. Adjournment
 - a. Dr. Bettinger motioned to adjourn, Dr. Gannon seconded.
13. Adjourned at 1:11 PM?