KANSAS NEWBORN SCREENING ADVISORY COUNCIL MEETING

ONLINE VIA ZOOM MEETING

MINUTES

MAY 20, 2021

Members Present

Emily Barr, Dr Jennifer Gannon, Dr Carolina Beltran, Karen Braman, Dr Grace Brouillette, Julie Wellner, Dr Kourtney Bettinger, Dr Merlin Butler, Meghan Strenk, Dr. Laurie Gwyn, Michelle Leeker,

Members Absent

Dr. Susan Pence, Dr. Brittan Zuccarelli, Shobana Kubendran, Dr Mike Lewis, Karey Padding, Dr. Selina Gierer, Dr. Thomas Loew, Jessica Vail,

KDHE Staff Present

Michelle Black, Drew Duncan, Dustin Caldwell, Heather Smith, Kinsey Anderson, Casey Guccione, Michelle Mills, Phillip Davis, Rupinder Kaur, Patrick Hopkins, Melaine Klessler-Mathiue, Marilee Lowrey, Shane Morris, Rachel Sisson, Ryan Jones

Others Present

Randi Gadea, Paul Roesch (Baebies), Bryce Heese, Brenda Bandy, Treva Smith, Denise Dobson, Jennifer Marsh, Michelle Knoll, Emily Brinkman

ACITON ITEMS:

1. Committee to send feedback and questions about adding a breastfeeding question to the NBS
    a. *DUE: May 31, 2021*
2. 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?
    a. *DUE: May 31, 2021*
3. Committee to review and provide feedback on new Invalid Specimen Parent Letter
    a. *DUE: June 1, 2021*
4. Committee to respond with any suggestions for the new website
    a. *Due: June 30, 2021*
5. Kinsey to add question about meeting format (in person, hybrid, virtual) to next AC survey
    a. *Due: July 23, 2021*

Meeting Recording:

Link:
https://us02web.zoom.us/rec/share/z6cdws9Zmi4s81jHwXFRswyDG_DG7KN1W1oDFrAyJ4kOA8zN_jmpAfhpjHbLCYWk.Tvm_WyDyP3usTCxf

Access Passcode: KSNBSAC52020!

Minutes

1. Housekeeping
    a. Attendees introduced themselves via Zoom name display and answered icebreaker question in the chat
    b. Approval of previous minutes (with no edits): Dr. Kourtney Bettinger moved to approved and Dr. Gwyn seconded.
2. Breastfeeding and NBS
    a. Brenda Bandy & Treva Smith presented breastfeeding data and how we can utilize the information.
        i. KS does not ask feeding questions
        ii. National recommendation is to ask feeding questions.
        iii. Other states are asking feeding questions.
        iv. Data from vital birth record does not accurately reflect whether mother is breastfeeding at discharge – facilities are instructed to select "yes" if mother *ever* breastfed before discharge
        v. Data would provide county and facility level data regarding intensity of breastfeeding (Human milk, formula, or both) which is not currently available
        vi. Would also provide demographic race and ethnicity data to support breastfeeding equity initiatives
        vii. Discussion about potential impact that simply asking the question could have on facility initiative to promote breastfeeding – particularly for non "Baby-Friendly" facilities (only 7 "Baby-Friendly" facilities in KS right now)
        viii. Will continue discussion internally and revisit the topic at the next Advisory Council Meeting with opportunity to vote
        ix. **ACTION: request committee feedback, thoughts, and questions on this topic by June 1, 2020**.
3. Data Survey
    a. Preferences: Scheduled vs. Survey
        i. 50% of respondents had no preference.
    b. Conclusion
        i. Will continue scheduled review and survey
    c. Data topics preferences:
        i. Timeliness: review each meeting
        ii. Presumptive Positive cases and Positive predictive value/false positive
        iii. Lost to follow up: review each meeting.
    d. Data review schedule for future meetings.
        i.
            - **January**
                - Timeliness
                    - Time from birth to diagnosis
                    - Time from birth to false positive determination (for refer level abnormal screens)
                - Presumptive Positives
                - Lost to Follow Up
                - Positive Predictive Value & False Positive Rate
                - False Negative Rate
            - **May**
                - Timeliness
                    - Collection Time
                    - Transit Time
                - Presumptive Positives*
                - Lost to Follow Up*
                - Unscreened Infants*
            - **September**
                - Timeliness
                    - Time from receipt to report
                    - Time from birth to report
                    - Time from report to medical intervention
                - Presumptive Positives
                - Lost to Follow Up
                - Unsatisfactory Specimens
        ii. No objections to this plan were voiced

e. Timeliness:
    i. 2019: Program began timeliness education
    ii. Currently live webinars and custom webinars.
    iii. Aug 2020 Sunday courier project.
f. Time of collection:
    i. 2019 avg 36.92 hours
    ii. 2020 avg 35.45 hours
    iii. 2021 avg 52.66 hours
g. Steady decrease in collection time through 2019 and early 2020
h. Follow up experienced staffing transition in Sept 2020.
i. Current efforts for improvement
    i. Increase frequency of webinars.
    ii. Monthly newsletter reminders.
j. Transit time: from time of collection to receipt at lab.
    i. 2019 avg 70.93 hours
    ii. 2020 avg 62.70 hours
    iii. 2021 avg 64.23 hours
k. Transit time has improved year over year
l. Activities for improvement
    i. Launch of timeliness tips poster March of 2020
    ii. APHL Sunday Courier project Aug 2020
m. Impactful events
    i. Covid shutdown
    ii. Reduce in education activities from 9/20 to 2/2021 due to staffing transitions
n. Lost to Follow up:
    i. What we need to present the data -definitions.
        1. Working with hearing to align definitions across whole program.
        2. NewSteps:
            a. Only requesting lost to follow up counts on infants that have a specimen.
            b. Infants without a specimen are counted separately
        3. Follow up acts on infants without a screen. Should these be counted in lost to follow up if unresolved?
    ii. Lost to follow up data project updates
        1. While evaluating the data, became aware that some infants were not counted that should have been. Raised questions about definition of lost to follow up.
        2. Continuing to evaluate data before presenting results
o. ACTION: Program requests committee feedback on new data presentation format (presenting data in context of program activities). Is this helpful for you or too much information?

4. Overview of follow up protocols.
    a. Notifications from KHEL
        i. REFER level

ii. Rescreen level – follow up further differentiates these for follow-up-action purposes
    1. Repeat
    2. Borderline
iii. Unsat
iv. Invalid

b. Initial follow up actions
    i. REFER
        1. Call and fax to PCP
        2. Letter to parents
        3. Some disorders, call specialist
    ii. Repeat
        1. Call and fax to PCP
        2. Letters to Parents
    iii. Borderlines
        1. Fax to PCP (no phone call)
        2. Letter to parents
        3. "Borderlines" are treated differently for three reasons:
            a. Volume of "Borderlines" for some conditions (TSH, HgB, LSD rescreens) – don't have the capacity to call all of these
            b. They are not time-critical and we have not observed problems with PCPs following through on follow up's recommendations
            c. HgB follow up takes a lot longer (9-12 months)
    iv. Unsat
        1. Call to PCP
    v. Invalid
        1. NICU -track call at 14 days if no recollection
        2. Well Baby – Call immediately

c. General subsequent follow up.
    i. 14 Days and/or
    ii. 30 Day and/or
    iii. 90 Days
    iv. Specific timing and number of times we follow up depends on the specific condition.
    v. One condition (SMA) gets a call again in 24-48 hours after initial contact; also use professional/contextual judgement to call on specific cases that we feel will benefit from another call in 24-48 hours
    vi. Dealing with changes to PCP:
        1. Verify patient is following in the practice; if not, inform physician of legal obligation to inform family and identify which practice baby is following in.
        2. Carry out same follow up actions with new PCP information.
        3. Voicemails: request provider return call to confirm receipt of information and verify infant is following in the practice.

4. Parent letters sent for every condition that we screen for
    a. Informs family of out of range result for XYZ condition
    b. We have XYZ PCP on record, ask family to call program if incorrect.
    c. Prepared at same time as call and fax to PCP – families may receive letter after follow up actions already taken (factor of postal service).
    d. Serves as safety net protocol.

d. Other follow up questions form the data survey.
    i. What data does the follow up team track?
    ii. When does follow up consider the "time form reporting out of range results to a medical intervention" complete?
    iii. Need more time to answer questions with enough context – will add to agenda for next meeting.

e. New Parent letter for invalid results.
    i. A way to contact families about no valid screen on file when:
        1. When either been unable to communicate with PCP, or
        2. Have communicated the with PCP and still do not have a valid screen.
    ii. One last step before closing such cases.
    iii. Drafted and email to the council.
    iv. ACTION: Review and provide feedback by June 1.

f. New Parent letter for unscreened infants.
    i. We attempt contact with provider before closing without a screen.
    ii. Currently no protocol for where there is no known provider and no evidence of "no consent".
    iii. Not yet drafted reviewing hearing screening's letter and protocol.
    iv. Dr. Beltran asked if there could be improved education to help midwives and birthing facilities about completing the screens.
        1. NBS does actively educate birth facilities and midwives about providing complete information on the demographic cards
        2. Cases without PCP or birth facility information most often do not have blood spot specimens submitted to the lab (therefor no information from the demographic card).
        3. Cases without any information on the birthing facility or birth attendant or PCP most often come from Out-of-Hospital births were there may not actually be a birth attendant and the family has chosen to avoid any medical interventions.
        4. May be opportunity to work with Vital Records for educational opportunities/outreach to families submitting their own birth records.

5. KHEL updates
    a. KHEL is fully staffed. Also have covid staff helping out.
    b. Perkin Elmer Genetic specimen processor (GSP)
        i. Will replace Perkin Elmer AutoDelfia
        ii. Regarding CAH, CH and CF.

c. Sunday Courier Grant
    i. Improved transit time since start.
    ii. Improved number of specimens submitted.
    iii. Grant has been extended.
        1. Overnight shipping preprinted label trial
        2. Six-month trial
        3. For facilities <15 specimens per month
d. SMA: went live Feb 1, 2020.
    i. Two screen positives – both confirmed diagnosed
        1. 2020 SMN-2 type 3
        2. 2021 SMN-2 type 2
e. LSD 2nd tier updates
    i. Pompe 8 total sent to 2nd tier
        1. 6 neg from Mayo
            a. 4 indeterminate for sequencing
        2. 2 positive from Mayo
            a. 1 indeterminate and 1 positive
    ii. MPS-I 4 total specimens sent to 2nd tier
        1. 3 neg from Mayo all indeterminate for sequencing
        2. 1 uncertain from Mayo indeterminate for sequencing.
f. XALD Projected start of the certification and pilot 2021
g. References and acknowledgements
    i. Health Chem
    ii. New Steps
    iii. She also thanked lab staff and stated she was very proud of her team.
        1. Brandon Moreno, Rupinder Kaur, Justin Gianares, Casey Guccione

6. Education Updates
    a. Meet a Specialist Webinars
        i. LSD
        ii. Still in planning phase
        iii. Will be 30 minutes instead of 60
    b. Updating Materials
        i. NBS Brochure
            1. Adding SMA, Pompe, MPS-1, and X-ALD
        ii. Website
            1. X-ALD added by 3/2022
    c. New Materials
        i. Info Brief/Info Sheet for Providers and Families
            1. Will do one for each disorder – updating what's currently available on our website to be less text heavy and more user friendly
            2. Will you use LSD info brief as template
        ii. Abnormal Parent Letter insert finished – getting Spanish translation
            1. Will be permanent
        iii. NBS Brochure insert finished – getting Spanish translation

1. Temporary until new brochure

iv. Combo Brochure
1. Covers different Bureau of Family Health programs from conception to adulthood (through the life course)
2. QR codes will link to specific program websites

v. Screening Card Handling Instructions
1. 2-sided document included with NBS cards
2. Instructions on how to handle safely w/pictures – useful for facilities and to reduce unsatisfactory specimens
3. Possibly laminated to be able to keep

vi. Facility Recognitions
1. Best of Best for 2020
2. Based on 2019
3. Due to COVID-19, thought about not adding some data, but feedback has been to keep it
4. New category: Most Improved
5. May use Percentile vs. meet or exceed goal for qualification due to impact of COVID-19
6. Meeting near end of May

vii. Website update
1. Complete overhaul
2. Will take a year, but making changes as needed in the meantime
3. Will be easier to navigate and have enhanced search feature
4. Taking suggestions
5. Using Minnesota NBS website as base model – information is easy to find. https://www.health.state.mn.us/index.html
6. Will be designed for KS
7. **ACTION: respond with suggestions for website by end of June**
8. Julie Wellner asked if we are using ACMG Act Sheet – Kinsey responded KS ACT sheets are based on ACMG sheets, but also tailor it to KS needs.
    a. Part of information on website for physicians. Clarified that each condition has information on the website, but text heavy and difficult to understand, particularly ones for families. Will be more user friendly.

7. Subcommittee Updates
    a. 2 committees have met – Metabolic and X-ALD
    b. Metabolic
        i. Updated cutoffs for 3 conditions
            1. VLCAD
            2. IVA
            3. GA-1
        ii. Lab collecting data on VLCAD to determine if new ratio is better
        iii. Will continue to send spreadsheet of analyte and ratio data to Specialists upon request

iv. Will continue to meet every 3 months

c. X-ALD
    i. Began meeting monthly in March
    ii. Gathering background info about impact of screening
        1. Robust committee with specialists (endocrinology, neurology, & metabolic), families, and program partners
    iii. Drafting white paper
    iv. In planning phases of education and communication materials
    v. In process of informing agency partners
    vi. Bid process for equipment is closed and in review
    vii. Will pilot in late 2021 and plan to go live in 2022

d. New/Re-Establish Committees
    i. Endocrinology
        1. Kinsey asked for volunteers to serve subcommittee – Endos, family practice, pediatrics, families
        2. Dr. Michelle Knoll
        3. Kinsey will reach out to Endos, family practice and peds to see if they will serve
    ii. Hemoglobinopathy
        1. Taking 2nd look at protocols of Sickle Cell and Sickle Cell traits
            a. Would like to have volunteers from family practice, pediatrics, midwifery, as well as Specialists
            b. Kinsey will reach out to others as well

8. New Business / Discussions
    a. Shane pointed out Dr. Butler's chat comment regarding potential breastfeeding factors. Kinsey will save and share with Kansas Breastfeeding Coalition
    b. Marilee pointed out previous question about voting on adding breastfeeding question to NBS card
        i. Kinsey noted some barriers, such as lack of space on demographic card
        ii. Ongoing conversation
        iii. Will put on agenda for next AC meeting, maybe vote at next meeting
            1. **ACTION: committee to send any additional questions/thoughts by end of the month**
    c. Kinsey will send out reminder of deadlines for various feedback requests
    d. Dr. Butler – if KS wants to be a forerunner in breastfeeding forum
        i. Consider publishing in public health journal – commentary section
        ii. And other areas as well
        iii. Dr. Butler is editor of 3 of the journals
9. Next Meeting scheduled for 9/23/21
    a. Courtney – hybrid option or in person possibly?
        i. Kinsey replied not sure yet, but the Zoom option has been very helpful for everyone being able to attend, so that will always be an option
        ii. Maybe have in person once/year?
        iii. ACTION: Kinsey will add the question to the next AC survey

10. Motion to Adjourn
    a. Shane Morris
    b. 2nd by Dr. Butler
11. Adjourned at 12:45 PM