

KANSAS NEWBORN SCREENING ADVISORY COUNCIL MEETING

ONLINE VIA ZOOM MEETING

JANUARY 21, 2021

MINUTES

Members Present

Emily Barr, Dr Jennifer Gannon, Dr Carolina Beltran, Karen Braman, Dr. Brittan Zuccarelli, Dr Grace Brouillette, Julie Wellner, Dr Kourtney Bettinger, Dr Merlin Butler, Shobana Kubendran, Meghan Strenk, Dr Mike Lewis, Laurie Gwyn, Karey Padding

Members Absent

Thomas Loew, Susan Pence

KDHE Staff Present

Michelle Black, Daniel Ellsworth, Drew Duncan, Dustin Caldwell, Heather Smith, Kinsey Anderson, Casey Guccione, Michelle Mills, Phillip Adam, Phillip Davis, Megan Specht, Rupinder Kaur, Patrick Hopkins, Justin Gianares, Kathy Modin, Melaine Kessler-Mathieu

Others Present

Charlotte Buchanan, Dennis Dobson, Randi Gadea, Hari Patel (Baebies), Jon Washburn (Baebies), Paul Roesch (Baebies), Bryce Heese

1. Housekeeping
 - a. Attendees introduced themselves via Zoom and shared their hope for 2021
 - b. Approval of previous minutes (with no edits): Mike Lewis made a motion to approve and Dr. Bettinger Motion approved.
2. Previous Meeting Action Items:
 - a. Review Cutoffs for VLCAD: Cutoffs have been submitted to P&E. Have meeting this week. COMPLETED
 - i. Everything's ready to go with the Lab's side - waiting on P&E to implement. Time Frame?
 - ii. Will also involve IVA/C5 cutoff (second cutoffs based on weight)
 - b. CMV with dried blood spot. COMPLETED
 - i. Shobana sent information about screening with blood spot.
 - ii. Blood spot is not as sensitive as urine. Requires a 2nd tier testing.
 - iii. Urine screening is simple and sensitive but may be practical for a subpopulation.
 - c. Establish Education subcommittee and Outreach committee. COMPLETED
 - i. Committee has been formed and is currently meeting monthly.
3. New Staff Introductions:

- a. Shane Morris – NBS Education and Outreach Coordinator.
 - b. Justin Gianares – Microbiologist at KHEL.
- 4. NBS Updates –
 - a. LSD Live -Went live Jan 4th, 2021.
 - i. Implemented borderline category - asking for a repeat NBS.
 - ii. Initial Screen - Pompe (GAA) and MPS-I (IDUA)
 - iii. 2ndTier-
 - 1. Mayo Biochemical
 - 2. Babies targeted Next Generation Sequencing
 - b. Pilot Started May 14, 2020 > 28,000 specimens
 - i. Screened for four LSDs
 - ii. Improved specificity for Pompe and MPS-I
 - iii. Resulted in more specimens sent to 2nd tier and higher cost
- 5. Lost to Follow up data
 - a. Project: Analyze Lost to Follow-up (LTF) data of our NBS programs
 - i. Staff will be BFH SR. Epi and Epi intern; S&S Staff
 - 1. Timeline: 10-12 weeks
 - ii. Goals (s)
 - 1. Attempt to identify who may be at risk of LTF based on demographic information
 - 2. Develop targeted educational and outreach materials based on identified needs
 - iii. Status:
 - 1. Epi staff reviewing data dictionaries
 - 2. Working through parameters of data pull (how many years of LTF data are necessary?)
 - 3. Bi-weekly meetings with epi staff throughout the completion of the project.
- 6. Education Updates:
 - a. LSD Webinars:
 - i. Webinar planning group members established
 - ii. First planning meeting pending doodle poll – Friday deadline
 - iii. Estimated Timeline:
 - 1. Planning phase (January 15, 2021 to January 29, 2021)
 - 2. Marketing/communications phase (January 29, 2021 to February 5, 2021)
 - 3. Implementation phase (February 1, 2021 through April 30, 2021)
 - 4. One-hour time limit for webinar (suggested)
 - b. LSD Social Media Campaign – complete & submitted to communications
 - c. LSD Press Release – distributed January 5th
 - d. LSD News Media – January 6th featured story on KMBS & KCWE news and online
 - a. <https://www.kmbc.com/article/kansas-now-screening-newborns-for-two-additional-disorders-for-early-detection/35138593#>

- 7. Education Continued- New Materials
 - a. Kansas Newborn Screening Brochure
 - i. Receiving feedback from EOC
 - ii. Send reminder and give deadline by January 19, 2021
 - iii. New information
 - iv. SMA
 - v. Pompe
 - vi. MPS I
 - vii. X-ALD
 - b. Updating Website with new disorder information
 - c. Info Brief/Info Sheet for Providers and Families
 - 1. One for each disorder we screen for
 - 2. Need same information as listed on the LSD brief
 - 3. Will be linked to Kansas NBS Website
 - d. Abnormal Parent letter Insert
 - i. Kansas NBS Brochure Insert: Temporary Use Only
 - ii. Will be replaced once Brochure is updated
 - e. Webinars for metabolic disorders
 - i. One Webinar to cover all metabolic disorders?
 - ii. Multiple webinars?
 - 1. Fatty Acid
 - 2. Organic Acid
 - 3. Amino Acid
 - 4. Hemoglobin
 - 5. Misc
 - iii. Specialist or someone from KHEL to speak on webinars
 - iv. Create Slides Presented by KDHE (~15 minutes)
 - 1. Screening Methods
 - 2. Screening Algorithm & Possible Results
 - 3. Reading the Lab Report
 - 4. What to do when Abnormal Result is Received
 - 5. Available Specialists for each disorder
 - v. Obtain Slides to be presented by specialist (~45 minutes)
 - 1. Disorder Basics, Hallmark Symptoms, Immediate Clinical Actions, etc.
- 8. KHEL Updates:
 - a. Staffing –we will be fully staffed Feb 1, 2021
 - b. CLIR data uploaded for 2020
 - c. Presented at APHL NBS Symposium
 - i. Oral Presentation
 - ii. Two poster presentations
 - d. Lysosomal Storage Disorder Harmonization Project completed

- i. Analyzed QC materials provided by CDC for Pompe and MPS-I
 - ii. Collaborated with CDC and 11 other states to test varying levels of enzyme activity with post-analytical data analysis performed by Tennessee.
 - e. Sunday Courier Grant
 - i. Sunday Courier started Aug 2, 2020
 - ii. Average participation rate 21 out of 29 facilities
 - iii. Average Number of specimens received 24 hours soon at KHEL = 150
 - iv. Data reviewed by APHL – improved transit time by 1.35 days
 - v. Remember to send specimens daily
 - vi. Have the ability to add to the route, if a facility is interested.
 - f. Covid assistance:
 - i. Staff assisting in the evening
 - ii. Staff assisting when needed during the day, holidays, and weekends.
 - 1. Despite assisting with Covid still about to maintain TAT.
 - g. Turnaround Time for NBS
 - i. Time critical 35.3 hours
 - ii. Newborn screening 27.6 hours
 - h. SMA Update
 - i. One SMA screen positive since go live date of February 1, 2020.
- 9. Subcommittee conversations:
 - a. Role of Subcommittees
 - i. Provide subject matter expertise to guide programmatic decisions and planning, Including assisting with necessary research
 - ii. Provide stakeholder perspectives
 - iii. Serve as a vehicle for the review of special topics and related data
 - iv. For clinical conditions committees, Meet as needed to support periodic review of cutoff values.
 - 1. New conditions – once live, committee remains established and can meet quarterly or semiannually for a period of time to review data and assist with any necessary adjustments to protocols and cutoff values
 - 2. Established conditions – some may need to meet periodically or only as needed
 - v. Report back to Council at each council meeting
 - b. Expectations of Subcommittee Members
 - i. Attend committee meetings as scheduled
 - ii. Actively participate and contribute to committee activities, including
 - 1. Any necessary research
 - 2. Document development
 - 3. Data review
 - c. Metabolic Subcommittee
 - i. Purpose:
 - 1. To assist with the development and ongoing review of methodologies and protocols that guide

2. screening and follow up activities, periodically review data relevant for screening sensitivity and specificity, and assist with updating cutoff values for metabolic conditions.
 3. People willing to participate: Jen, Bryce, Meghan, Randi, Shobana, Carolina
- d. SCID/SMA Subcommittee
- i. Purpose:
 1. To assist with updating cutoff values for SCID
 - a. Michelle Mills had a list of who was in the SCID subcommittee and will send to Kinsey
10. Data Discussion
- a. Establish schedule for presenting data
 - b. Targeted details within context
 - c. Reserve cutoff reviews and detailed disorder results information for subcommittees
 - d. Clarify what data council wants to review
 - i. Dr. Gannon clarified that FP should include FP and trait /carrier. Only dx should be included in the DX category not trait.
11. Working lunch - Council viewed the News interview announcing going live for <https://www.kmbc.com/article/kansas-now-screening-newborns-for-two-additional-disorders-for-early-detection/35138593#>
12. X-ALD Updates
- a. Michelle Mills explained adding XALD will change all Mass Spec values and it will take time to adjust the instruments.
13. New Business:
- a. Refusals for NBS.
 - i. Dr. Bettinger asked about refusals and how to document them.
 - ii. Discussion was that religious beliefs would be the only reason to refuse a screen.
 - iii. Recommendation would be to put a form on the website.
 - iv. KDHE asked providers to have parents sign a document stating they understand the risks of not completing the screen and keep that in their file and send a copy to KDHE follow up.
14. Next Meeting – May 20, 2021
15. Adjournment –
- a. Dr. Bettinger made a motion to adjourn and Julie Wellner seconded it.