

## **NEWBORN SCREENING ADVISORY COUNCIL MEETING – ONLINE VIA MICROSOFT TEAMS**

May 28, 2020

### **Members Present**

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

### **Members Absent**

Thomas Loew, Susan Pence

### **KDHE Staff Present**

Michelle Black, Alyson Huber, Daniel Ellsworth, Drew Duncan, Dustin Caldwell, Heather Smith, Jennifer Evans, Kinsey Anderson, Casey Guccione, Liz Schardine, Kathy Modin, Leo Henning, Michelle Mills, Molly Still, Myron Gunsalus, Phillip Adam, Phillip Davis, Megan Specht, Rupinder Kaur, Shawn Manos, Patrick Hopkins

### **Others Present**

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

1. Housekeeping
  - a. Attendees introduced themselves via Microsoft Teams
  - b. Approval of previous minutes (with no edits): Dr Lewis motioned to approved, Shobana seconded.
2. Previous Meeting Action Items:
  - a. When giving data reports please break down by analyte with a note of which disorder the analyte associates with –
    - i. Complete
  - b. Request for Qi5c (time from receipt by KHEL to time final report generated by KHEL) broken down by time critical results –
    - i. KHEL will continue to look into this – Horizon upgrade did not allow for this to be completed at this time
  - c. Fee for service discussion has been tabled until May a/c meeting to address if KDHE needs to explore the option for a fee for screen.
    - i. Update given during Statute Updates portion of meeting
      1. Statute cap was raised to \$5m, but only for 1 year.
  - d. Discuss simultaneous notification of PCP and specialist for SMA at the same time.
    - i. Complete? Will follow up with 24 hours to ensure specialist has been contacted.
    - ii. Shobana requested this be further discussed but during Subcommittee meeting, not AC.
3. NBS program updates.

- a. Grants:
  - i. CDC new conditions grant Y2 continuation application
    - 1. Ending Sept 2020
    - 2. Used to add SMA, adding LSD's and start X-ALD discussion.
- b. APHL grant
  - i. Asking for funding to help establish a Sunday courier to specific birthing facilities.
- c. Education
  - i. NBS timeliness poster.
    - 1. Printed and shipped
  - ii. New quick reference
    - 1. Midwives and physician toolkit published
    - 2. Birthing facility is next.
  - iii. Comprehensive list of NBS competencies/ KS train training
  - iv. In development - suggested script for talking to families about NBS
  - v. "best of the best" 2019
    - 1. Facilities divided by births per year.
  - vi. Outreach Jan through May
    - 1. 12 facilities plus midwives 39% contact
    - 2. 7 in person trainings 20% since Oct.
    - 3. Wichita area tour 7 facilities 8 sessions 56 individuals
    - 4. Upcoming blood spot collection technique webinars. 1<sup>st</sup> two weeks of June.
    - 5. Blood spot recollection guidance during COVID-19
      - a. Increase in repeat screening
      - b. Guidance on recollecting during reopening phase
      - c. In home collection alternatives for possible future stay at home orders.
    - 6. **Action Item:** Identify health departments or facilities that can be a point of collection for each county.
  - vii. Unsat 2019 4.76% now 4.17 through Q1 of 2020%
  - viii. Unsat codes shown per quarter
  - ix. Statewide trend of 930 coming down
  - x. Statewide trend of 950 staying the same
  - xi. Statewide trend 941 spike in 2<sup>nd</sup> quarter
- d. KHEL update:
  - i. Updating the LIMS system. LIMS update is to include a web-based portal. PCP will be able to access the reports through the portal.
    - 1. Manage expectations of the portal, it is a big project. Horizon 12 upgrade will be completed but the portal will be the next step.
    - 2. Anticipate having the system updated by the end of 2020 and the first quarter of 2021, users will be able to access their reports via portal.
    - 3. **Action Item:** Update on the portal progress.
  - ii. Analyzing 6 days a week

- iii. Sunday courier grant awarded
      - 1. 29 facilities
      - 2. Finalizing bids
      - 3. CLIR data upload for 2020 in progress
    - iv. LSD harmonization project
      - 1. Partnering with CDC and with 11 other states
    - v. Staffing
      - 1. New staff Rupinder Kaur
      - 2. one staff resigned.
    - vi. COVID-19
      - 1. One NBS FTE assisted with COVID -19 from March to April
      - 2. One Saturday NBS staff assisting April to current
      - 3. NBS staff assisting with data entry and processing early morning and evening.
  - e. SMA- KS now screening for SMA Live Feb 1, 2020
    - i. No Presumptive positive screens since going live.
  - f. LSD pilot began May 14, 2020
    - i. Estimated go live 4<sup>th</sup> quarter 2020
    - ii. LSD 2nd tier testing targeted Next generation sequencing.
      - 1. Will include Pseudo deficiency and CRIMS status
  - g. X-ALD
    - i. Estimated optimization of tandem quadrupole Mass spec July to august 2020
    - ii. Estimated start of verification of Neobase 2 - 4<sup>th</sup> quarter 2020
    - iii. Estimated started of x-ADL pilot 1<sup>st</sup> quarter 2021.
- 4. Follow-Up update
  - a. KHEL is running business as usual
  - b. Follow up will be working remotely with potential limited in office hours.
  - c. Bureau realignment almost complete.
  - d. Second coordinator position has been posted and interviews are pending.
  - e. Statute updates: K.S.A. 65-180
    - i. Budget proviso Gov Kelly did sign bill allow for an increased cap to \$5m and only for 1 year.
      - 1. Because only 1 year increase, some long term initiatives like contracts with specialists, will need to be readdressed at a later date.
    - ii. The way they worded it, it did not include the language clean up. Only changed section (l) wording for cap funding that such amount should not exceed \$5 million for FY2021.
    - iii. Will have to go back later this year and open statute again to make it permanent and clean up outdated language.
- 5. Data discussion:
  - a. 2019 abnormal case report. More active case follow up.
    - i. NICU - 284 FP with 18 dx.
    - ii. Well baby - 143 FP and 70 dx.

- b. Per previous meeting Action Item, data was broken up into categories (organic, fatty, amino acid, Misc.) then further identified using Disorder flagged for. Previously done by analyte and was confusing.
    - i. It was clarified that a baby could flag in multiple categories.
  - c. Dr. Gannon commented that this was helpful information.
  - d. Gave updates on when items were called out
  - e. CCHD update.
    - i. Screens improving.
    - ii. 2018 9% not screened 2019 and 2020 2% not screened.
  - f. What should follow up consider false positive.
    - i. **Action Item:** Anything that flags or only the presumptive positive? This will be a program discussion and determined before the next AC meeting to ensure reporting consistency.
6. LSD overview
- a. As of May 1<sup>st</sup>. screening for all 4 LSD (Pompe, MPS-1, Fabry, Gaucher) during Pilot Phase.
    - i. If multiple LSD's flag, specimen quality will be questioned. Specimen will be Indeterminate and a repeat will be requested
  - b. KHEL has a few for second tier testing at this time – results pending Baebies
  - c. During pilot, KHEL and subcommittee will be watching specificity of just Pompe and MPS-1 to determine if more efficient to screen for all 4 LSD's (or just Pomple/MPS-1) will be tested for when we Go-Live.
    - i. Number of specimens flagged and/or are False Positives will help determine
7. Recommendations for PCP's not following protocol.
- a. **Action Item:** smaller subcommittee to discuss details below.
    - i. Important to document when PCP or nurse has stated they do not want follow protocol.
    - ii. Educate both nurse and doctor. Nurse is likely doing what they are asked to do.
    - iii. Genetics would comment that it becomes the burden of the clinic if they get calls
    - iv. Dr. Lewis stated follow up had a good sense of when to contact the specialist.
    - v. Should there be a geographical distribution for who gets notified?
    - vi. Shobana stated too much burden for follow up to determine if the PCP is willing to call the specialist.
    - vii. Gannon states all screens/babies are important and we should not be triaged into what is important and what is not.
    - viii. Kinsey large impact of education.
    - ix. Dr. Lewis spoke at KAPA committee and a lot of the care of babies in Kansas is not Pediatrician, but family care and PA. Education needs to be with groups and associations.
    - x. Dr. Bettinger stated that she sees PCP are really busy and are given lots of information and it may not be important until they have a positive screen.
    - xi. Consider adding web addresses to the fax cover page.
    - xii. Ease of access to finding the fact sheets. A quick link to click on next steps.
8. Comments and Discussions:

9. Next Meeting Sept 17<sup>th</sup> 2020.

a. Location to be announced or if will be held virtually (on-line again)

10. Meeting adjourned at 1:25.