

AC Newborn screening meeting

September 19, 2019

Members Present

Carolina Beltran, MD
Merlin Butler, MD
Deborah Stern
Jennifer Gannon, MD
Julie Wellner, RN
Karey Padding
Meghan Strenk
Michael Lewis, MD
Shobana Kubendran MBBS, MS, CGC

Members Absent

Dee Spade, DO
Jakica Tancabelic, MD
Jean Stork
Kenneth Goertz MD
Michelle Ruebke, CPM
William Randall Reed, MD
Vance Lassey, MD
Susan Pence, MD
Grace Brouillette, MD
Selina Gierer, MD
Michelle Leeker

Staff Present

Heather Smith
Jan Conklin
Jennifer Evans
Michelle Black
Michelle Mills
Myron Gunsalus
Shawn Manos
Megan Specht
Alyson Huber
Phil Davis
Sarah Chicchelly

Others Present

Bryce Heese, MD
Charlotte Buchanan
Dennis Dobson
Randi Gadea
Candice Brannen
Kourtney Bettinger

- A. Housekeeping, welcome and introductions.
- B. Approval of minutes from Previous meeting.
 - 1) Karey Padding moved to approve the minutes
 - 2) Michael Lewis seconded to approve the minutes.
- C. Action items previous meeting:
 - 1) Unsat process trial – informed council that the trial was cancelled and we went back to calling Unsats each day and KHEL contacts the facility.
 - 2) False Positive vs. diagnosed cases is completed and will be presented later in the council meeting.
 - 3) PPV for different methods of screening for LSD's. – KHEL has reached out to other states and determined they did not see a difference in testing methods. KHEL proposes that they continue with Baebies and do second tier testing with identified cases.
 - 4) What other states labs are using MS/MS for LSD's and what is their feedback.

- There was discussion for second tier testing for and what we would find. How we would find VOUS and what to do with them. Dr. Gannon stated that she likes the Baebies screening.
- Dr. Butler stated that we need to be clear about our language we use terminology that is accepted by the genetic world.
- Myron had a question about second tier testing for CF also. He will contact Dr. Lewis at a later time.

D. General program updates:

- 1) NewSTEPs timeliness grant: Grant has ended but we continue to work on timeliness
- 2) CDC New conditions grant Y2 continuation application
 - Y2 grant begins Oct 1 2019
- 3) HRSA state evaluation grant award.
 - Ends Sept 30, 2019 and electronic reporting are being developed to provide feedback to the on their timeliness.
- 4) Statute updates
 - Heather gave a history on the statute.
 - Program is proposing an increase in the amount that is funded annually to the program.
 - Current funding comes from medical fee fund. The money in the medical fee fund comes from HMOs that pay into that account.
 - Shobana asked if there was a plan in place to look at pros and cons of charging a fee. Heather stated that at this point there are no plans to change to charging a fee to families for NBS.
 - Heather and Myron stated if the increase does not get approved then we will have to have a conversation on charging for screening.
- 5) Education updates:
 - DOB and TOB policy change
 - Have seen a decrease in errors after this change.
 - Unsat Process:
 - KHEL is now contacting the submitting facilities to provide them a photo of the Unsat card.
 - Educational outreach
 - Updated parent brochures
 - New educator begins 9/23/2019
 - Moving forward:
 - Need for increase trust between PCP and program recommended next steps.
 - KHEL update
 - HBG has been moved to HPLC – currently running
 - Currently running pre-pilot testing on Kansas specimens for SMA
 - Fully staffed at this point.
 - Phlebotomist on staff with KHEL who is working with facility to collect satisfactory specimens.
 - Saturdays reviewing data from Friday and having f/u contact

- Ready to move forward with Saturday accessioning of specimens
 - Due to Saturday accessioning, Please do not hold specimens
 - New staff Sarah, Casey and Dustin.
 - Follow-Up:
 - Staffing announcements: Kinsey Anderson starts on 9/23/2019 as the educational coordinator.
 - Reported that we have done a process review and which staff are completing specific tasks. Have planned for how to handle Saturday calling out. F/U is updating SOP's.
 - FP and Dx case report:
 - Provided the council FP and Dx cases for all disorders and SCID disorder separately. Dr. Gannon recommended comparing it to the total number of births in the month, so we could determine the FP rate.
 - NewSTEPs Quality indicator data report 2019.
 - % of Unsat specimens that are received at KHEL is in a downward trend.
 - % of >10 days had a spike in June and it is on a downward trend.
 - % of missing essential demographics overall downward trend.
 - F/U timeliness 355 specimens were called out within 24 hours. 1 was called out at 25 hours and 2 were low risk reported on a Saturday and called out on a Monday.
 - Newborn screening lab timeliness: Per the slides presented.
 - Left hand table correlates to the right pie chart and visa versa.
 - Handouts were given to the council on data for timeliness.
 - In 2018 there were 25% of the specimens reported out greater than 7 days, 2019 there has been 15% of the specimens that were reported out greater than 7 days (initial screens only).
 - Showed 2017, 2018 and 2019 birth to collection timeliness.
 - Birth to collection
 - Collection to receipt
 - Receipt to report
 - Birth to report (initial only)
- 6) CCHD updates:
- Past -2014 began education
 - Present - 2017 CCHD was mandated and documents were created.
 - Future - regulations are being submitted. Every baby born in KS will be screened for CCHD and reported to KDHE.
 - Searching for funding to assist midwives with purchasing of Pulse ox screening equipment.
 - CCHD Screening results reporting.
 - On par for the number of babies screened for CCHD.
 - No screen information provided to us is trending downward.
 - 2018 9% were no screen and 2019 were 2 % were no screen.
 - Reasons not screened.

- Home birth, error in charting, deceased, discharged, no consent and other.
 - FP rate for 2019. 62 total failed screens for 2019. 3 were found positive and 19 had other heart conditions.
 - Education:
 - Presented at 2 midwife symposiums
 - Presentations
 - Metabolic screening
 - Importance of Baby's first week in timeliness
 - Blood spot collection practices, Unsat and Critical information
 - CCHD pulse ox screening.
 - Screening results are on the electronic birth record.
- 7) SCID algorithm update:
- Follow up presented the new algorithm for SCID.
 - It will focus on gestational age and for babies < 37 weeks gestational age we will recommend repeating after two weeks to allow baby to stabilize.
 - Algorithm charts were shown for both <37 weeks and > 37 weeks.
- 8) Working lunch: Midwife Experiences in NBS video
- 9) Follow up reviewed the progress with SMA.
- Reported that the SMA subcommittee has met and we will review the documents created and move forward.
 - KHEL stated that they will be ready to screen when the documents are finished.
 - Heather Smith mentioned possible ideas for communication to the public once we are ready to go live.
- 10) New disorders:
- **Action item:** Myron requested that LSD subcommittee be formed and meet before the end of the year. New conditions grant ends Sept 2020 and we would like to be testing before them.
 - Julie motioned, and Dr. Beltran seconded.
- 11) Voting members were reviewed and council was informed that we need to replace 6 members. We are looking for a variety of different specialties and parents. If you have anyone you would like to recommend, please contact program staff.
- 12) New Business:
- Voting members – needs to update current list and website.
 - KHEL showed slides on updating the cut off for 3 conditions.
 - **C3** – Current Abnormal flag Cutoff for > 144 hours old is 3.09 µmol/L. Proposed Abnormal flag Cutoff for > 144 hours is 4.12 µmol/L
 - **GA-1** Current Abnormal flag Cutoff is 0.39 µmol/L. Proposed Abnormal flag Cutoff is 0.48 µmol/L
 - **C16OH** - Current Abnormal flag Cutoff for 0.06 µmol/L. Proposed Abnormal flag Cutoff for is 0.08 µmol/L

- **CIT** - Current Abnormal flag Cutoff is 40.22 $\mu\text{mol/L}$
Proposed Abnormal flag Cutoff is 54.77 $\mu\text{mol/L}$
 - Shobana posed the question about Kansas moving to a referral center.
 - Dr. Gannon likes the way MO does it and it ensures that every REFER screen is seen in a timely manner
 - Dr. Heese said that he liked the way that MO has a referral center with a contract.
 - Referral centers for MO are financially compensated
 - Dr. Butler stated about we are comparing apples to oranges because KS is disproportionate on where our two main hospitals are located
 - Specialist that Shobana has talked to are asking if they would be compensated for their time for subcommittees, AC council and being a champion.
 - Dr. Lewis stated that he gets paid off on their RVU when they are a champion for NBS. Shobana stated they providers overbook the day after and the day before taking a day off to support NBS.
 - Referral centers would take out the confusion if the first contact was from genetics or the appropriate specialty.
 - With referral centers they would not have to be physically close. Work up could happen over the phone.
 - As we move to new conditions treatment for rare diseases will not happen locally. They will have to travel to large cities. How do we help these families where they are?
 - GC are concerned about how to identify who to call and follow up will send out a list of who to contact for each condition.
 - Dr. Bettinger said that the website has been helpful.
- 13) Discussion about using GoToMeeting so members could see slides close up.
- 14) **Action item:** Request that KHEL will continue to give metrics.
- 15) Dr. Gannon motioned to meet quarterly with all the new conditions being brought on.
Motion Approved.
- 16) Next meeting: Thursday January 16, 2020
- Shobana ended 28 minutes early and Dr. Gannon seconded Shobana is the best chair. 😊