

KSNBS Advisory Council Meeting

Oct 25, 2018

Members Present

Carolina Beltran, MD
Merlin Butler, MD
Deborah Stern
Grace Brouillette, MD
Selina Gierer, MD
Jennifer Gannon, MD
Julie Wellner, RN
Susan Pence, MD
Karey Padding
Meghan Strenk
Michael Lewis, MD
Michelle Leeker
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

Staff Present

Ben Olson
Caryn Masters
Heather Smith
Jan Conklin
Jennifer Evans
Kayzy Bigler
Mary Hinze
Michelle Black
Michelle Mills
Myron Gunsalus
Shawn Manos

Others Present

Andrea Atherton
Bradley Schaeffer
Katlyn Akins
James Casey
Jane Diaz
Louis Diaz
Becky Ruth
Jesse Gale
Holly Kramer
Bryce Heese, MD
Charlotte Buchanan
Dennis Dobson
Jamey Kendall
Patrick Hopkins
Rachel Sisson
Randi Gadea
Robert Moser, MD

1. Welcome and introductions.
2. New council members and staff. Did not do
3. Action items
 - a. Unresolved and from May 3rd
 - i. Online data base. Still in progress
 - ii. Hemoglobin subcommittee will be developed- pending
 - iii. Should secondary analytes be added to current abnormal letters
 1. Pending metabolic subcommittee

2. Ability of LIMS to do so

- iv. Standpoint of PPV need to be added to the table-complete
 - v. Add XALD endo and Neuro along with genetics- complete
 - vi. Email this form to the AC so they have it electronically- complete
 - vii. Wesley is still getting 20% of the specimen results greater than 7 days from collection more details on tracking specimens and when it's getting reported- KHEL.
 - viii. Dr. Lewis asked how the states that bill for NBS did so and who they bill-Each state is different some include it in the hospital bill and some bill insurance. NewSTEPS has most of this data available online.
 - ix. Provide links to watch videos from CureSMA - complete
 - x. CureSMA has a good Algorithm for each type of SMA (0-4) get copy of this - complete
 - xi. Re-work SCID algorithm to include very small BW babies (<500g) - Dr. Greier is working on it
 - xii. Re-work SCID algorithm to include babies with at least one normal screen- complete
 - xiii. Dr. Hesse asked that someone from KDHE would travel to Hunter's Hope in July- Incomplete- Travel not approved.
 - xiv. Dr. Gannon was asked to be Vice Chair and she said YES!
4. Michelle Leeker and son Zack Leeker. Michelle's son died of Krabbe.
- a. Recommending adding Krabbe to panel. Secretary of KDHE could approve to add anything to the dried blood spot. Heather and Myron believed the approval to add condition to screening panel could pass after research on how the condition would impact the NBS program. It was in the May 2018 minutes to include it in the strategic planning.
 - b. 3 kids have been dx in the state of Kansas that the family network is aware of at this time.
 - c. It will be presented to the RUSP again. MO did not wait for it to be approved by the RUSP before adding it to their panel.
 - d. Michelle gave cost perspective for her family: \$700,000 spent in 21 months to keep a Krabbe child comfortable. Cost of transplant vs. cost of screening should be considered.
 - e. Dr. Pence would like to find a champion at CMH that would be willing to do the transplant.
 - f. Action: put Krabbe on the chart with the other 4 possible conditions and include in analysis for program capacity in the Strategic Planning**
 - g. Jessie's son Brady was diagnosed at 4 months with Krabbe. Brady passed away 10 days before his 1st birthday. Family started a petition to educate about Krabbe in 2008, passed petition in 2009. Jessie met Ezra who was born with Krabbe in 2018 and was transplanted at Duke because of screening for Krabbe in MO. Becky Ruth, Jessie's mom, helped to expand screening in MO. Family worked with MO NBS screening to screen for Leukodystrophies. MO has changed the lives of 120 babies since screening for Leukodystrophies. Ezra's journey documents his process through transplant and can be found online.

- h. There is not a cure for Krabbe, but a treatment. First child transplanted passed away in 2018, but it did give him more life. “We don’t say we can’t do anything because there isn’t a cure for Cancer, we do what we can for treatment while we look for a cure.” Zach Leeker
 - i. Treatment is transplant, stem cell transplant. Some kids deal with graft vs. host. The transplant has come a long way. There can be side effects to treatment but according to Zach and the friends that he had most of the side affects are minor.
 - j. The petition was for education about the disease.
- 5. Dennis and Jamey Strategic Plan
 - a. Conduct PEAS
 - b. Review NewSTEPS from 2015 and 2017
 - c. Review surveys of stakeholders.
 - d. Missed
 - e. Missed
 - f. Missed
 - g. NewSTEPS Assessment Recommendations Status Table
- 6. Current Grant
 - a. NewSTEPS timeliness grant.
 - i. No cost extension through April 2019
 - ii. Report cards to facilities to give them feedback on their own timeliness.
 - b. CDC New Conditions Grant Award
 - i. SMA
 - c. HSRA State Evaluation Grant Award
 - i. Data Enhancements
- 7. Regulations Updates
 - a. KAR Collection Time Revision from 72 to 48 hours.
 - b. CCHD Regulations
- 8. KHEL updates: Introduce Ben Olson Laboratory Manager
 - a. Bio-Rad Variant -NBS Hemoglobin Testing System
 - i. New go live Dec-Jan
 - b. NBS Reporting updates- Effecting 10-1-18
 - i. Cause: Submission from missing birth/collection. Date time or specimen <24
 - ii. No more corrections
 - c. UPS Pilot Project
 - i. M-Sat shipments to 7 birthing facilities.
 - ii. Timeliness grant did increase the timeliness for hospitals in Western Kansas. It was not helpful across the board.
 - d. CDC new condition grant. Purchase validate equipment and new laboratory instrumentation. Plan to expand to SMA.
 - e. Holidays at KDHE
- 9. Education
 - a. Birthing Facility Survey
 - b. Education for Collection Staff
 - i. Baby’s First Week Graphic

1. Passed them out.
 - ii. Site Visit
 1. Western Kansas 10 Facilities
 2. Shawnee Mission NICU and well-baby
 3. KU Medical Center
 - iii. Future Projects
 1. QA spot check
 2. Spanish combo brochure
 3. Training videos-Debra stated that videos could be linked to Hospital association.
 4. State Logo-AC liked the logos on the right but wanted more color on the left.
 5. Holly asked if the big facility has liaisons for education.
 - a. Dr. Beltran asked if Mary has been able to identify champions at each facility.
10. False Positive Rates and Birth to Report
- a. NewSTEPS time reporting
 - b. Need to have an explanation for anything reported outside of the national timeliness goals
 - c. Action Item: Shobana made a motion to ask for quality indicators data listed on NewSTEPS before the next AC meeting. Julie Wellner seconded.**
11. Reviewed fees charged by each state and discussed how a fee could be charged
- a. CF homebirth with no insurance.
 - b. Action item cost analysis for financial structure review for all 5 conditions what would we recommend.**
 - c. Hearing has bundled hearing into the hospital practice.
 - i. MO has a fee \$95. Also, no family is denied screened based on inability to pay. Small fee goes to midwives and homebirths.
12. Dr. Shaffer would like to recommend storing for testing for CMV. Storage for normal is 30 days. Abnormal are stored indefinitely.
- a. Action Item Shobana motioned to discuss spot storage and retrieval of blood spot storage and include Newborn Hearing Screening. Dr. Casey seconded.**
13. New Business
- a. Late day specimen: specimen cannot be run until 10:30. The cut is 10:30 because that is when FedEx guarantees delivery.
 - i. Jamey said we need a common courier.
 - ii. MO has 56 couriers on the system. If they have a baby a day a courier would go check for specimens. If the hospital has less than a baby a day they are responsible for getting the specimen to the lab or a facility participating in the courier.*
 - b. Hemoglobin contract, Wichita medical research review.
 - i. Are we duplicating effort?
 - ii. What should a person do if they want their NBS result.
 - iii. No objections to continuing the contract.

- iv. Anyone is welcome to email Jamey Kendell.
- v. **Action: SMA Committee to be formed**
 - 1. Mr. and Mrs. Diaz, Dr. Beltran, Kayzy Bigler, Cure SMA and Biogen. (conflict of interest) a Dr. that would follow up with them. Rehab medicine at CMH
- c. **Action: Subcommittee for education**
- d. **Action: Second tier testing for CAH- Shobana made a motion and Dr. Casey second Shobana**

14. adjourn.

May 16th next meeting.

Action Items:

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- b. **Shobana made a motion to ask for quality indicators data listed on NewSTEPS before the next AC meeting. Julie Wellner seconded.**
- c. **Cost analysis for financial structure review for all 5 conditions what would we recommend.**
- d. **Shobana motioned to discuss spot storage and retrieval of blood spot storage and include Newborn Hearing Screening. Dr. Casey seconded.**
- e. **SMA Committee to be formed**
- f. **Second tier testing for CAH - Shobana made a motion and Dr. Casey second Shobana**