

NBS Advisory Council – Online via Microsoft Teams

September 17, 2020 @10:00am

Members Present

Carolina Beltran
Kourtney Bettinger
Jennifer Gannon
Shobana Kubendran
Michelle Leeker
Michael Lewis
Karey Padding
Meghan Strenk
Julie Wellner
Laurie Gwyn
Grace Brouillette
Jessica Vail

Members Absent

Merlin Butler
Thomas Loew
Susan Pence
Emily Barr
Selina Greier
Debra Stern
Brittan Zuccarelli

KDHE Staff Present

Kinsey Anderson
Michelle Black
Daniel Ellsworth
Jennifer Evans
Michelle Mills
Heather Smith
Megan Specht

Marilee Lowrey
Casey Guccione
Rupinder Kaur
Liz Schardine
Drew Duncan

Others Present

Charlotte Buchanan
Dennis Dobson
Randi Gadea
Hari Patel
Karen Braman
Bryce Heese
Jon Washburn
Paul Roesch

1. Welcome and announcements: Introductions
2. Approval of minutes:
 1. Dr. Lewis motioned to approve, and Dr. Gannon seconded.
3. Action Items from Previous Meeting:
 1. See details on slides 6 and 7
4. General NBS Program Updates:
 1. Grants and special project updates
 - i. See details on slide 9
 2. Educational Updates
 - i. Kinsey showed the resources available on our website.
 - ii. Dr. Gannon recommended that we vet resources through our committee for approval.
 - iii. Dr. Gannon asked to table the discussion on resources and education subcommittee will approve. Review next 24 hours and education subcommittee will review within 2 weeks.
 1. Gannon motioned and Lewis seconded.
 - iv. First Annual Facility Recognition
 1. See details on slide 14
 2. Webinar data, see details on slide 15

5. KHEL Updates:
 1. Staffing- One opening.
 - i. CILR data was uploaded for 2020
 - ii. APHL symposium invited Kansas
 1. KS oral presentation and 2 poster presentations.
 2. Sunday Courier- No cost to facility paid for by grant from APHL.
 - i. Started Aug 2, 2020
 - ii. Improved transit time by 1.35 days
 - iii. Biggest improvement was babies born on Wed through Sat.
 - iv. Compared 7 facilities that did use Courier vs. facilities that did not use courier.
 3. Covid Update:
 - i. Staff was shared to assist with Covid. And currently is only assisting on the evenings.
 4. Conditions SMA, LSD, and X-ALD
 - i. No positive SMA since we went live. We expect one in 25,000
 - ii. LSD Pilot started May 14, 2020
 1. See details on slide 29
 - iii. X-ALD: Plan to Pilot and bring on 4th quarter of 2021.
 5. Shobana gave a shout out to the lab for taking initiative to pilot and make improvements.
6. Follow up updates:
 1. Covid 19: working remotely and in office
 2. Staffing and Bureau Realignment
 - i. Staff updates
7. Data Discussion
 1. False Positive and diagnosed case review
 - i. Shobana asked if doing 2nd Tier testing would bring down false positive results.
 - ii. Dr. Gannon expressed concern over the number of carriers that NBS is picking up. **Action Item: review cut offs for VLCAD.**
 - iii. Timeliness of follow up. 97% of results called out in 24 hours
 2. NewSTEPS Quality Indicator Data
 - i. Follow-up timeliness – 97% cases reported out within 1 day (goal = 95%); See details on slide 46
 - ii. See NewSTEPS Quarter 1 handout for full details of all other Quarter 1 measures
 3. Unsat specimen trends
 - i. 12-month average = 4.18% as of July 2020
 - ii. Spike in April – possibly due to COVID-related staffing changes
 - iii. Significant increase in 941 codes (blood on the coverlet)
 - iv. Overall, rates continuing to trend downward
8. Point of Care updates
 1. CCHD
 2. Hearing
 - i. Covid is affecting follow up screening due to families postponing follow up testing.

**3. Action Item: Surveillance Team How would we go about adding the CMV screening.
Shobana will send some information**

9. Working Lunch: NBS saves lives videos

10. LSD updates

1. Subcommittee recommendations.
 - i. No cost savings for screening 4 vs. 2 LSD screens
 - ii. Added downstream cost to follow up and specialist
 - iii. Treatments not indicated for NBS period
 - iv. Need more data on reliability of Fabry screening method for females
 - v. Screens not on RUSP (only one part of the discussion)
2. Next Steps
 - i. Submit formal recommendation to Dr. Norman
 - ii. Detail education plan and timeline
 - iii. Execute a communications plan 30 days prior to go live.
 - iv. Planning for a Dec 1 go live date.
3. Education Committee: Needs for review.
 - i. Not following CF recommendations.
 - ii. Reporting forms not being returned in a timely manner.
 - iii. Best way to contact PCP.
 - iv. Specialist collaborations.
4. Council Chair nominations.
 - i. Shobana nominated Dr. Gannon for chair and Dr. Lewis second.
 - ii. Shobana nominated Dr. Beltran for vice-chair and Kari Padding seconded.
 - iii. Dr. Lewis and Laurie Gwyn voted to close nominations and Karry seconds.
 - iv. Dr. Gannon and Dr. Beltran accepted nominations.
 - v. The Council voted to elect Dr. Gannon as Chair and Dr. Beltran as Co-Chair
5. Comments or New Business
 - i. Shobana thanked the Council for their help, feedback and support.
6. New Business
 - i. None listed.
7. Adjourn.
 - i. Dr. Gannon voted to Adjourn and Karey seconded.