

Virginia Newborn Screening Advisory Committee
Thursday, June 18, 2020
10:00 AM – 11:00 AM

Location: Virtual Meeting via Zoom

Conference call-in phone number: 1-929-205-6099 Access Code: 830 7154 8506

Webinar Link: <https://us02web.zoom.us/j/83071548506?pwd=SmFBMThuTHludU1NbDlmSW5CQm0ydz09>

Platform: Zoom Meeting ID: 830 7154 8506 Password: NBSAC2020!

AGENDA

Members (Bold = present):

- | | |
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| <ul style="list-style-type: none"> <input type="checkbox"/> Dr. Bill Wilson, UVA, Chair <input type="checkbox"/> Abraham Segres, VHHA <input type="checkbox"/> TBD, CNMC <input type="checkbox"/> Julie Murphy, Parent <input type="checkbox"/> Karen Shirley, HCA-Va, Chippenham Hospital <input type="checkbox"/> Lisa Shaver, Children’s Hospital of Richmond at VCU <input type="checkbox"/> Amber Price, American College of Nurse Midwives <input type="checkbox"/> Rachel Gannaway, Genetic Counselor, VCU <input type="checkbox"/> Dr. Christian Chisholm, UVA, ACOG <input type="checkbox"/> Dr. Michael Martin, Virginia chapter AAP <input type="checkbox"/> TBD, Community Pediatrician | <ul style="list-style-type: none"> <input type="checkbox"/> Marie Pokraka, MOD <input type="checkbox"/> Jana Monaco, NORD, Parent <input type="checkbox"/> Dr. Hind Al Saif, VCU <input type="checkbox"/> Dr. Samantha Vergano, EVMS/CHKD <input type="checkbox"/> Dr. Brooke Vergales, Neonatologist, UVA <input type="checkbox"/> Kim Pekin, CPM <input type="checkbox"/> Barb Goodin, Dietician, UVA <input type="checkbox"/> Dr. Stephanie Smith, DOD, Portsmouth Naval Medical Center <input type="checkbox"/> INOVA, TBD |
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VDH & DCLS Staff

- Christen Crews**
- Emily Hopkins**

10:00 – 10:10	<p>Welcome: Dr. Bill Wilson, Chair</p> <p style="padding-left: 40px;">A. Role Call of Members and Interested Parties</p> <p style="padding-left: 80px;">a. Dr. Wilson opened the meeting and welcomed attendees in the new virtual format. A role call of NBS AC Members was held.</p> <p style="padding-left: 40px;">B. Approval of November 14, 2019 Meeting Minutes</p> <p style="padding-left: 80px;">a. The November 14, 2019 meeting minutes were approved by the attending NBS AC voting members.</p> <p style="padding-left: 40px;">C. Review of Agenda</p>
10:10 – 10:20	<p>Public Comment</p> <p>Kasey Feldt: Ms. Feldt spoke about her son Dawson (11 months old). He was diagnosed with Krabbe at 6 months of life. She wishes they had more time with him and she is asking for help in advocating for Krabbe to be added to newborn screening in Virginia.</p> <p>Lana Grujicic: Ms. Grujicic spoke about her son Nikola. She stated that for survival, Krabbe must be diagnosed within the first week of life and receive transplant by 1 month. If legislation is passed, future babies can be saved and they will not have to suffer like Nikola and Dawson.</p> <p>Aiel Russel: (Occupational Therapist): First NBS AC meeting and she thanks the council for having her and thanks our families for sharing their stories.</p>

10:20-10:25	<p>Statement to NBS Advisory Committee: Willie Andrews:</p> <p>Willie Andrews shares her gratitude and honor serving VA NBS program for the last 30 years, she stated she is proud of the work and how the program has grown and changed with the evolving needs of the newborn screening community of Virginia. She thanks the committee for sharing its experience and guidance.</p> <p>Dr. Wilson thanks Willie on behalf on the committee for all her work in the state and nationally in the newborn screening community. She has been an advocate for equality in newborn screening, timeliness and communication of results, and various other behind the scenes work.</p>
10:25 – 10:50	<p>Programmatic Updates</p> <ul style="list-style-type: none"> • SMA/X-ALD Implementation Updates, Christen Crews <ul style="list-style-type: none"> ○ Christen Crews, VDH, shared updates on the status of implementing SMA and X-ALD. The report to the Commissioner was submitted and the Board of Health was scheduled to meet in March; however, due to the impact of COVID that meeting was cancelled. The next quarterly meeting was June 4th, and Jennifer MacDonald, Division Director Child and Family Health, VDH, introduced proposed recommendation by the NBS AC to add SMA and X-ALD to Virginia’s core newborn screening panel. The Board of Health agreed to move forward with the regulatory process. After it moves through the executive branch review, there will be a period of public comment before it goes back to the Board of Health for review a final time. Although there is no exact date or timeline for implementation of screening for these disorders, actions for implementation are still moving forward internally. The state laboratory and follow-up program at VDH continue to meet weekly regarding implementation, methodology, validation, education, follow-up algorithms, infrastructure changes we need for LIMS (state database). These will prepare the program to move forward with implementation once the regulatory phase has passed. • COVID-19 and Virginia Newborn Screening, Christen Crews <ul style="list-style-type: none"> ○ There have been some reports of isolated difficulty of providers regarding collecting repeat screens. Some providers may rely on outpatient hospital labs for repeat screening and these labs have been closed due to COVID-19. The Virginia NBS program has provided education on collection techniques and practices, as well as modules for continuing education credits available at no charge. The program has coordinated with freestanding labs and health departments as needed if doctor’s office was unable to collect. The program has seen an increase in less than 24 hour collection, as hospitals are discharging babies as quickly as possible, resulting in a need for repeat screens.

The program has also seen some delays in confirmatory diagnostic testing and increase in telehealth use across the state.

- Electronic Messaging, Emily Hopkins
 - Newborn screening is a time sensitive public health program. The Virginia NBS program continues to support the national focus on timeliness and quality improvement. A lot of the process with communication of newborn screening orders and results are manual. The program is focusing on utilizing electronic messaging to improve timeliness of getting test results back to physicians so they can make decisions for possible treatments or follow up for these patients. In Virginia, 16% of hospitals are sending electronic orders and 2% of that are receiving results electronically. Additional hospitals are in development stages but COVID has impacted progress. A new opportunity was discussed collaborating with iConnect Consulting Inc to develop e-messaging tool to assist hospitals. DCLS will lead this 4 year project. The goal is for all hospitals to have every opportunity they can to establish electronic messaging. The program is looking for hospital partners to serve as a beta site.
- Timeliness Workgroup, Emily Hopkins
 - In the past the program utilized a Timeliness workgroup that would meet internally; however, due to competing priorities the workgroup has not been meeting. In recognition of the importance of timeliness, the program had a meeting back on June 9th. The workgroup will meet internally to review data for the report cards that are sent out to birthing hospitals. The program will be meeting virtual or in-person to have more productive communication and targeted QA/QI approach. In the past, the program has asked for volunteers to expand representation in the workgroup to include representatives from birthing centers, out of hospital birth provider communities, NICUs, nurseries, and other stakeholders around the state to look into what actions can be taken to improve timeliness.
- Data Review, Emily Hopkins
 - A review of data from 1/1/2019 – 5/31/2020 was shared with the NBS AC.
 - An unsatisfactory rate of 1.5 % of samples received was noted.
 - Over 134,000 infants screened, received over 147,000 samples, and diagnosed just under 5,000 babies.
 - Transit time: has decreased from under 3 days to around 1.5 days.
- Krabbe Workgroup, Dr. Wilson and Christen Crews
 - The program is soliciting people interested in participating in Krabbe disease review workgroup. Representation is requested to include:
 - Each of the genetic referral centers

	<ul style="list-style-type: none"> ▪ Out of hospital birth providers ▪ Parent Advocates ○ If interested in participating please reach out to Christen Crews. Once the workgroup has been configured, future workgroup meetings will be scheduled. Dr. Wilson advised to be prepared for a fair amount of offline work to be informed on moving forward with these discussions and recommendations.
10:50-11:00 AM	<p>Open Discussion/Adjournment</p> <p>Dr. Wilson: Has COVID need for molecular testing changed anything about the turnaround time for the 2nd tier testing for LSD or Cystic Fibrosis?</p> <p><i>Response: We did make guidelines for turnaround time for LSD sequencing, our aim is 4-6 weeks in the warmer months and 3-4 weeks in the cooler months. Our backlog is growing every day, so we are doing our best to turn those around as fast as we can and we appreciate everyone's patience.</i></p> <p>Question: Why does sequencing time vary depending on the temperature?</p> <p><i>Response: Warm temperatures degrade the enzyme. More samples are flagged for 1st tier and then need sequencing. Sequencing process is long and labor intensive so the more samples we get that need sequencing the longer it takes.</i></p> <p>Question: What is the cost for hospitals to implement electronic messaging?</p> <p><i>Response: Unfortunately, there is no defined cost and it does vary. It depends on available resources that the hospital has, the path of how they want to implement and what needs they are working with. There are ongoing costs but we are willing to work with direct hospital resources if available or are able to collaborate with one of the vendors. If there is an interest, contact Emily Hopkins to continue the conversation and be able to give more specific defined costs depending on what they have to work with.</i></p> <p>Comment: Delegate Kathleen Murphy was successful in getting legislation passed in the General Assembly to mandate insurance companies to cover medical formula and foods for conditions on the NBS panel.</p>

Next meeting date: November 12, 2020