

**Virginia Newborn Screening Advisory Committee**

**Thursday November 12, 2020**

**9:00 AM – 12:00 PM**

**Location:** Virtual Meeting via GoToWebinar

**Meeting Registration:** <https://attendee.gotowebinar.com/register/1115659465833922573>

**Platform:** GoToWebinar **Meeting ID:** *see registration email*

**Minutes**

**Members (Present= Bold):**

- |   |   |
|---|---|
| <input type="checkbox"/> <b>Dr. Bill Wilson, UVA, Chair</b>                         | <input type="checkbox"/> Marie Pokraka, MOD   |
| <input type="checkbox"/> Abraham Segres, VHHA                                       | <input type="checkbox"/> <b>Jana Monaco, NORD, Parent</b>                                 |
| <input type="checkbox"/> <b>Dr. Christina Grant, CNMC</b>                           | <input type="checkbox"/> <b>Dr. Hind Al Saif, VCU</b>                                     |
| <input type="checkbox"/> Julie Murphy, Parent                                       | <input type="checkbox"/> <b>Dr. Samantha Vergano, EVMS/CHKD</b>                           |
| <input type="checkbox"/> <b>Karen Shirley, HCA-Va, Chippenham Hospital</b>          | <input type="checkbox"/> <b>Dr. Brooke Vergales, Neonatologist, UVA</b>                   |
| <input type="checkbox"/> <b>Lisa Shaver, Children’s Hospital of Richmond at VCU</b> | <input type="checkbox"/> <b>Kim Pekin, CPM</b>  |
| <input type="checkbox"/> Rachel Gannaway, Genetic Counselor, VCU                    | <input type="checkbox"/> <b>Eileen Coffman, Registered Dietitian</b>                      |
| <input type="checkbox"/> Dr. Christian Chisholm, UVA, ACOG                          | <input type="checkbox"/> <b>Dr. Stephanie Smith, DOD, Portsmouth Naval Medical Center</b> |
| <input type="checkbox"/> <b>Dr. Jane Die, Virginia Chapter AAP</b>                  | <input type="checkbox"/> <b>Katie Page, American College of Nurse Midwives</b>            |
| <input type="checkbox"/> <b>Dr. Richard Bennett, Community Pediatrician</b>         | <input type="checkbox"/> <b>Dr. Marta Biderman Waberski, INOVA</b>                        |
| <input type="checkbox"/> <b>Dr. Sylvia Lee, Community Pediatrician</b>              |   |
- VDH and DCLS Staff**
- Christen Crews, VDH
  - Emily Hopkins, DCLS

9:00 –9:10	<p>Welcome: Dr. Bill Wilson, Chair</p> <p style="padding-left: 40px;">A. Role Call of Voting Members</p> <p style="padding-left: 40px;">B. Approval of June 18, 2020 Meeting Minutes</p> <p>The June 18, 2020 meeting minutes were approved by the attending NBS AC voting members.</p> <p style="padding-left: 40px;">C. Review of Agenda</p>
9:10 – 9:20	<p>Public Comment</p> <p><b>Anna Grantham:</b> From Hunter’s Hope Foundation in Buffalo, NY, Ms. Grantham stated that diagnosed babies born in states currently screening for Krabbe lives are vastly different than those of diagnosed babies born in states not screening. She asked that the committee give these babies the chance that they deserve.</p> <p><b>Rachel Lebrow:</b> Ms. Lewbrow spoke about her daughter, Mila, born in 2017 at Naval Medical Center in Portsmouth, VA. She shared the diagnostic odyssey to her diagnosis and potential alternative outcomes with earlier diagnosis.</p> <p><b>Dragan Grujicic:</b> Mr. Grujicic shared the story of his son, Nikola, diagnosed with Krabbe and speaks to the devastation of the disease and the toll of only being able to make him comfortable in his remaining days. Mr. Grujicic asks the committee to Vote yes to House bill 97.</p> <p><b>Lana Grujicic:</b> Shared a video from Krabbe Connect of children with Krabbe disease.</p> <p><b>Kasey Phelps:</b> Ms. Phelps is a Virginia resident and her son Dawson was diagnosed with Krabbe at 7 months old. Dawson very recently passed from complications of the disease.</p> <p><b>Stacey Pikes Langenfield:</b> President of Krabbe Connect, shares that screening has greatly improved and shares data from states currently screening for Krabbe.</p>

	<p><b>Dr. Alissa Kennedy:</b> Physician and advocate for newborn screening for Krabbe disease.</p> <p><b>Ann Rugari:</b> Parent and advocate, VP of Krabbe Connect. Ms. Rugari discussed the quality of life in treated compared to untreated patients. She speaks of the importance of parents having the choice to decide to treat.</p>
9:20 – 9:30	<p>Parent Perspective: False Positive Experience, Dr. Anna Irwin</p> <p>Dr. Irwin shared her experience of false positive lysosomal storage disorder newborn screening result and the negative emotional effects on her family.</p>
9:30 – 9:50	<p>Programmatic Updates: Christen Crews, Emily Hopkins</p> <p>A. Virginia Programmatic Updates</p> <p>a. CYSHCN Updates: Marcus Allen, MPH  Priorities and Updates: Emphasis on continuity of operations during COVID. Strong partnerships with medical centers, regular meetings with partners, keeping contracts and proposals current.  Biggest area of focus this year will be on health equity and needs assessment, identifying gaps in service with the Child Development Clinic (CDC) partners, discussion with DMAS to strengthen relationships between our care coordinators and Medicaid care coordinators</p> <p>b. VA Sickle Cell Awareness Program: Shamaree Cromatrie, MPH  Shared the ending of a project with Children’s National, analysis of the experience and preferences of parents of sickle cell trait positive children, trait notification needs to be improved and education to families improved. Masks and hand sanitizer care packages passed out to families.</p> <p>c. EHDI/cCMV: Deepali Sanghani, MPH  Code of Virginia updated to include targeted cCMV screening and include education to families, updated hearing result brochures, samples collected at birth facility and transported to DCLS, follow up for positive babies, developed protocols with advisory committee, detected 12 babies since 9/1/20</p> <p>d. Birth Defects(BDS)/CCHD: Katherine Crawford, MPH  BDS Key Activities: Completed Zika BDS activities, filled BDS Program Coordinator position. Current Initiatives: Developing BDS program evaluation plan, applying for five-year CDC grant opportunity, creating VDH BDS program advisory group  CCHD: Moved program under BDS program, confirmed diagnoses reported into VaCARES, referred infants to CCC  CCHD current initiatives: filling CCHD NBS Coordinator position, applying for five year CDC grant opportunity, preparing for possible AAP endorsement of revised CCHD screening recommendations</p> <p>e. Dried Blood Spot  Expansion of REDCap to other disorder groups (metabolic/genetics, hemoglobin, cystic fibrosis)-allows for reporting and more timely follow up and diagnosis/case reports, quality of data much improved.</p>

	<p>B. Electronic Messaging Project continues, started in 2013, using health information technology to improve timeliness through electronic demographic and order submission and result reporting, currently 19% of hospitals using e-messaging and still partnering with new hospitals, goal is to establish e-messaging with all of Virginia’s hospitals, new APHL-sponsored QI initiative: partnering with iConnect Consulting to develop e-message tools to assist hospitals, DCLS will lead the 4 year project, need hospital partners willing to serve as beta sites</p> <p>C. DCLS Connect Portal- NBS Results Portal went in 2019- provides electronic newborn screening results, to this date: 816 PCP’s registered, 620 PCP’s have accessed reports, 34,825 reports viewed</p> <p>D. NBS Data Review 2020 data: Over 78,000 infants screened, 2,511 babies diagnosed, 1.2% UNSAT, average transit times just over 1.5 days</p>
9:50 – 10:00	<p>New Business</p> <p>A. SMA/X-ALD Implementation Updates, Christen Crews Currently in regulatory process phase, in review by Secretary of Health and Human Resources, behind the scenes program is moving towards implementation (weekly team meetings, method set-up and validation, create algorithm, LIMS changes, workgroup, follow up and education preparation)</p> <p>B. LSD Screening Updates, Leigh Emma Lion and Paul Hetterich Screen positives from 1<sup>st</sup> tier are higher than expected, especially in the warmer, more humid months, impacting turnaround time significantly, Process improvements to mitigate the impact: implemented LSD sequencing workflow adjustments in Q2 2020 that tripled weekly sequencing capacity from 10 samples per week to 30-35, following population data evaluation, DCLS plans to adjust the IDUA critical cutoff in Q4 2020, investigating possibility of adding GAG testing as 2<sup>nd</sup> tier</p> <p>C. Next Meeting Dates- Spring(virtual) June 10th or June 17<sup>th</sup>, Fall/winter Dec 2nd or Dec 9<sup>th</sup>, watch for doodle poll</p>
10:00 – 11:40	<p>Krabbe Disease Review</p> <p>A. Delegate Jason Miyares, Virginia House of Delegates, 82<sup>nd</sup> District Sponsor of House Bill 97, Advocate for Krabbe Newborn Screening in Virginia, addressed the NBS AC Board Members and asked that Virginians be allowed the chance for screening for Krabbe Disease.</p> <p>B. Workgroup Presentation, Christen Crews a. Presented overview of Krabbe disease and findings of the three Krabbe disease workgroup meetings from the past few months.</p> <p>C. NBS AC Board Member Discussion, Facilitated by NBS Staff a. Discussion among the NBS AC Board Members to consider the recommendation to add Krabbe Disease to Virginia’s core newborn screening panel.</p> <p>D. Roll Call Vote, Dr. Bill Wilson 9 No, 6 Yes, 4 Abstain, recommendation did not pass at this time</p>

	<p>E. Next Steps, Christen Crews</p> <p>a. The complete report of the Krabbe disease discussion and workgroup findings can be found online at: <a href="https://rga.lis.virginia.gov/Published/2021/RD154/PDF">https://rga.lis.virginia.gov/Published/2021/RD154/PDF</a></p>
11:40 – 12:00 PM	Open Discussion/Adjournment