

**Virginia Newborn Screening Advisory Committee  
Thursday, June 7, 2018  
10:00 a.m. – 3:00 PM**

The Division of Consolidated Laboratory Services (DCLS)  
600 North 5<sup>th</sup> St. Room T21/T23  
Richmond, VA 23219

**Conference call-in phone number: 1-866-842-5779 Code: 804-648-4480**

**AGENDA**

**Members (check = present):**

- |   |   |
|---|---|
| <input checked="" type="checkbox"/> Dr. Bill Wilson, UVA, Chair                         | <input checked="" type="checkbox"/> Marie Pokraka, MOD (phone)                                  |
| <input type="checkbox"/> Abraham Segres, VHHA   | <input checked="" type="checkbox"/> Jana Monaco, NORD, Parent                                   |
| <input checked="" type="checkbox"/> Sarah Viall, CNMC (phone)                           | <input checked="" type="checkbox"/> Dr. Hind Al Saif, VCU                                       |
| <input checked="" type="checkbox"/> Julie Murphy, Parent (phone)                        | <input checked="" type="checkbox"/> Dr. Samantha Vergano,<br>EVMS/CHKD (Dr. Kelly Jones, Proxy) |
| <input checked="" type="checkbox"/> Karen Shirley, HCA-Va, Chippenham Hospital          | <input checked="" type="checkbox"/> Dr. Brooke Vergales, Neonatologist, UVA                     |
| <input checked="" type="checkbox"/> Lisa Shaver, Children’s Hospital of Richmond at VCU | <input checked="" type="checkbox"/> Kim Pekin, CPM  |
| <input checked="" type="checkbox"/> Amber Price, American College of Nurse Midwives     | <input checked="" type="checkbox"/> Barb Goodin, Dietician, UVA                                 |
| <input checked="" type="checkbox"/> Rachel Gannaway, Genetic Counselor, VCU             | <input type="checkbox"/> DoD, TBD   |
| <input type="checkbox"/> Dr. Christian Chisholm, UVA, ACOG                              | <input type="checkbox"/> INOVA, TBD   |
| <input checked="" type="checkbox"/> Dr. Sandy Lee Chung, Virginia Chapter AAP           |   |
| <input type="checkbox"/> Pediatrician, TBD  |   |

**VDH & DCLS Staff**

- Willie Andrews
- Jennifer Macdonald

**Interested Parties:** Christina Owens, Eileen Coffman (CHKD), Katie Crosby (CNMC), John Gibson (Biogen), Robin Buskey (VDH), Cornelia Deagle (VDH), Chris Nixon (DCLS), Richard Haughton (DCLS), Emily Hopkins (DCLS), Julia Shreckhise (DCLS), Denise Toney (DCLS), Ciera Plum (VDH), Jennifer Brickey (VDH), Lillie Chandler (VDH), Christen Crews (VDH), Angela Fritzingler (DCLS), Christina Stauffer (public)

10:00 – 10:20	<p>Welcome: Dr. Bill Wilson, Chair</p> <ul style="list-style-type: none"> <li>A. Welcome to DCLS: Dr. Denise Toney               <ul style="list-style-type: none"> <li>a. Dr. Denise Toney provided opening remarks and safety instructions while at the state laboratory.</li> </ul> </li> <li>B. Role Call – Quorum present</li> <li>C. Introductions of Members and Interested Parties               <ul style="list-style-type: none"> <li>a. Welcome to new advisory committee members: Dr. Sandy Chung, Marie Pokraka</li> </ul> </li> <li>D. Review of Agenda               <ul style="list-style-type: none"> <li>a. Dr. Wilson briefly reviewed agenda. No additions made.</li> </ul> </li> <li>E. Approval of December 7, 2017 Meeting Minutes               <ul style="list-style-type: none"> <li>a. Approved by members.</li> </ul> </li> <li>F. Travel Reimbursement (members only)</li> </ul>
10:20 – 10:35	<p>Public Comment: There was no public comment.</p>

<p>10:35-11:35</p>	<p>Virginia NBS program updates: Willie Andrews, Jen Macdonald</p> <p>A. February &amp; May 2018 Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) meeting updates</p> <ol style="list-style-type: none"> <li>a. February 2018 meeting reviewed cutoff/risk assessment for dried blood-spot analysis. SMA recommendation voted upon (8Y-5N) and sent to Secretary. Final recommendation pending.</li> <li>b. May 2018 meeting discussed newborn screening (NBS) education and training tools, an update of a GAMT deficiency pilot screening project, a review of the committee’s process for assessing the public health impact of adding new conditions to the RUSP and a review of quality measures for long-term follow-up and the impact to families and professionals.</li> </ol> <p>B. Virginia Programmatic Updates: Staff</p> <ol style="list-style-type: none"> <li>1. Early Hearing Detection &amp; Intervention (EHDI): Jennifer Macdonald for Daphne Miller        In Summer 2018, program will add text messaging as a follow-up tool to aid in parent follow-up. In collaboration with CDC, program launched an EHDI app at 4 pilot hospitals to aid in parent education and next steps in hearing follow-up. Learning Communities have been established in Northern Virginia and Central Virginia and will be piloted in other parts of state the end of 2018 and 2019. Hospital, Audiology and Primary Care Provider (PCP) protocols have been updated and approved by the Commissioner in early 2018. Contracts continue with VCU and UVA to continue Family to Family Services and the Hearing Aid Loan Bank, respectively</li> <li>2. Sickle Cell Screening/Program Update: Christen Crews for Shamaree Cromartie.        Work continues to update blood disorder education material and reviewing to adjust cutoffs for reporting out of Barts Hemoglobin, fast band percentages, to providers.</li> <li>3. CYSHCN Updates: Christen Crews for Marcus Allen.        In April 2018, the first summit of all Virginia Children and Youth with Special Health Care Needs (CYSHCN) programs was held in early 2018 Care Coordination Centers (CCC), Child Development Centers, (CDC), Bleeding Disorders and Sickle Cell programs were all represented. Work continues with University of Virginia (UVA) on creating a web module for medical home and transition.</li> <li>4. Critical Congenital Heart Disease Screening (CCHD): Christen Crews        Passive surveillance continues. Diagnosed infants identified in VaCARES are confirmed and referred to CCC. Some cases with reversed diagnoses (after surgery) have been identified..</li> <li>5. Dried Blood Spot Follow-up (DBS): Christen Crews        Follow-Up Nurse Retreat was held in May 2018. Discussions centered around revamping follow-up processes – moving from task-oriented processes to case management for more timely resolution of open cases. “Just in time” education was presented- program will be drafting</li> </ol>
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	<p>education sheets for providers to receive when reporting critical values and will request respective consultant oversight.</p> <ol style="list-style-type: none"> <li>6. VCU Capstone Project: Willie Andrews Detailed early spring Capstone project with three Virginia Commonwealth University (VCU) students that focused on finding effective ways to educate parents and healthcare professionals about NBS. Methods included surveys, focus group, webinars, partnership with Baby’s First Test, and arranging pilots with 2 OB-GYN practices for dissemination of NBS education material.</li> <li>7. NewSTEPS 360 grant updates: Willie Andrews, Jennifer Macdonald Explained history of APHL/NewSTEPS and the current status of implementation of the two grants Virginia is involved in. Focus of one grant is to utilize HIT for order submission and result reporting. Currently five hospitals in production, with INOVA hospitals coming onboard. There are ongoing efforts to actively engage all hospitals. Second grant is a collaborative effort with New York Mid Atlantic Consortium (NYMAC) and focuses on assessing education on the effects on NBS collection and timeliness. ACHDNC timeliness measures were reviewed and outcome of both grants is to improve timeliness/accuracy through electronic messaging and education. Virginia activities related to current timeliness recommendations include: 1) added 13 hospital courier sites statewide; 2) added Sunday pickup to all hospitals; 3) monitor of hospital transit time and visit “top offenders”; 4) distribution of monthly report cards; 5) implementation of UPS courier service for midwives and birthing centers; 6) expansion of testing and follow-up to six days/week; and 7) hospital participation in the internal timeliness workgroup.</li> <li>8. NBS Data Review: Willie Andrews, Jennifer Macdonald. Reviewed 2017 data, highlighting the number of diagnosed cases and noting that time sensitive critical reports were reported 100% within days of receipt as of 3/2018(when expansion of hours to Saturday occurred). Review of continued improvement of transit time across state was discussed, including publishing hospital transit time publicly on both VDH and DCLS websites.</li> </ol>
11:35 – 12:00N	<p>Old Business</p> <ol style="list-style-type: none"> <li>A. 2018 GA update: Willie Andrews, Jennifer Macdonald The 2018 GA session was discussed including sharing the two stories of the families who advocated for the bills that were in the session. NBS staff worked with legislators on adapting bill to meet needs of program. HB1174 and SB449 focused on the addition of Pompe and MPS-1 to Virginia’s panel and HB1362 focused on the expansion of laboratory hours for time-critical results to 7 days a week and holidays. No General Fund appropriations were made.</li> <li>B. CAH screening: Chris Nixon Update provided on moving to 2<sup>nd</sup> tier CAH screening. The goal is to eliminate false positives from elevations in 17-OHP that can be seen when under stress or premature. Progress has been made in optimizing DBS</li> </ol>

	<p>extraction and creating material in-house for validation purposes. Input from endocrinologists is currently being ascertained. A new Senior Scientist has been recruited to focus on 2<sup>nd</sup> tier CAH and 1<sup>st</sup> tier LSD screening.</p> <p>C. Status Report- LSD screening implementation: Willie Andrews, Jennifer Macdonald</p> <p>Grant activities for LSD implementation were discussed for both the laboratory and follow-up program. Goal is to implement by January 2019 in conjunction with expansion to seven day screening.</p> <p>D. Status Report: Expansion to six and seven days/week: Willie Andrews, Jennifer Macdonald</p> <p>Program moved to 6 days a week in March 2018 (including holidays) for time-critical disorders with expectation of 7 days a week by January 2019.</p> <p>E. Regulation Review: Jennifer Macdonald</p> <p>Two disorders are scheduled to be reviewed as additions to the Virginia NBS panel in the next few months and will provide an opportunity to combine possible regulatory action of adding those disorders and a comprehensive regulation review. Program will keep committee updated as that time approaches for possible workgroup formation and volunteers.</p>
12:00 N – 12:30 PM	<p>New Business</p> <p>A. Fee increase: Willie Andrews</p> <p>Fee increase will need to incur in order to cover the addition of the two new disorders, Pompe and MPS-1, expansion of hours, and the future addition of X-ALD and SMA (if approved to be added). No estimate of fee increase amount is available at this time. Current fee is \$78. Some members voiced that Medicaid does fully reimburse and is charged separately from other maternity care. Kim Pekin, CPM, stated CPMs are not fully reimbursed by Medicaid for the NBS.</p> <p>B. SMA workgroup planning: Jennifer Macdonald</p> <p>Volunteers will be requested by email for participation in a SMA workgroup to meet in September.</p>
12:30	Break and Lunch Set-up
12:45 – 1:30	<p>Working Lunch</p> <p>Guest Speaker: Michele Caggana, Sc.D. FACMG Deputy Director of the Newborn Screening Program, New York State Department of Health, Wadsworth Center.</p> <p><i>New York's Experience in X-ALD Newborn Screening</i></p>
1:30	<p>Adjournment</p> <p>NBS-AC Workgroup: Review of X-ALD meeting following adjournment</p>

Next meeting date: November 15, 2018