

Virginia Newborn Screening Advisory Committee
Thursday, June 13, 2018
10:00 a.m. – 2:00 p.m.

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

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

MINUTES

Members (check = present):

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

- Willie Andrews
- Jennifer Macdonald

Interested Parties: Eileen Coffman (CHKD), Chris Nixon (DCLS), Richard Haughton (DCLS), Brittany Stone (DCLS), Denise Toney (DCLS), Gretchen Cote (DCLS), Jennifer Brickey (VDH), Christen Crews (VDH), Daphne Miller (VDH-phone), Shamaree Cromatrie (VDH-phone), John Gibson (Biogen-phone), Leigh Emma Lion (DCLS), Paul Hetterich (DCLS), Lindsey Sawyer (CHKD), Dr. Crystal Proud (CHKD-phone), Dr. Stephanie Smit (Portsmouth Naval –phone), Tammi McKinley (CPM, Virginia Midwife Alliance-phone), Katie Page (Centra Health – phone)

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| 10:00 – 10:20 | Welcome: Dr. Bill Wilson, Chair A. Welcome to DCLS: Dr. Denise Toney a. Dr. Wilson opened session and introduced Dr. Denise Toney. Dr. Toney welcomed the committee to DCLS. B. Roll Call C. Introductions of Members and Interested Parties a. Committee members and interested parties present in person and on the phone introduced themselves. D. Review of Agenda E. Approval of November 15, 2018 Meeting Minutes a. Minutes were approved unanimously. F. Travel Reimbursement (members only) |
| 10:20 | Public Comment: No public comment. |

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| <p>10:20-11:20</p> | <p>Virginia NBS program updates: Willie Andrews, Jen Macdonald</p> <ul style="list-style-type: none"> A. National front: ACHDNC meeting updates & 2019 NBS Symposium notes <ul style="list-style-type: none"> a. Minutes & presentations are posted on the Committee’s website: https://www.hrsa.gov/advisory-committees/heritable-disorders/meetings/index.html b. In April, the NBS team attended the 2019 Newborn Screening and Genetic Testing Symposium in Chicago. This conference facilitates a collaborative environment with all stakeholders in one room. Major topics included QA/QI, updates on new conditions, and molecular techniques. Gretchen Cote (DCLS) was selected for a poster presentation on gene sequencing. B. Virginia Programmatic Updates <ul style="list-style-type: none"> a. At the end of 2018, DCLS hired 2 NBS laboratory managers. In May, Cornelia Deagle, Division Director of Child and Family Health at VDH resigned. b. CYSHCN: Title V grant application and progress report due in July. CCC child development programs are all funded from this program. c. Sickle cell: Shamaree Cromartie is currently working on a study with CNMC. The goal is to interview parents of infants who screened positive for sickle cell trait to see how counseling experience has gone for them in order to see how we can improve our program at the state. VA is applying for a CDC grant that will build funding for sickle cell surveillance system. d. CCHD: Hiring a new contractor to continue program objectives. e. Birth defects: Now ending Zika project. Applying for CDC grant-NAS f. EHDI: Program has purchased 68 new hearing aids so far this year. Hosted the first Care Project Retreat in May. This is a program from NC, where organizers come to your state & it allows parents & professionals to come together. g. DBS: New phone system with one programmatic number. Each nurse has a direct extension. Now merging files for follow up into LIMS, which aims to improve efficiency by working within one system. h. NBS Data Review: Time critical disorders are run every day. There is a national goal for 24 hour transit time. Virginia is currently averaging 1.5 days. Most likely due as a result of sending report cards, currently and adding couriers. i. Electronic Messaging Project Continues: Currently in 4th year of project. DCLS is capable of sending electronic results to hospitals. Norfolk will be first hospital for orders & results. Sentara will soon join. NBS Program goal is to establish electronic messaging with all of VA’s hospitals. Feedback has been positive and has included that not having to handwrite and less time intensive detective work finding correct info when it’s wrong has been beneficial. DCLS receives acknowledgements of received results. Primary care |
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| | <p>providers will receive paper results still. Abraham Segres suggests sending an update to hospitals to congratulate early adopters, & bring hospitals up to speed on status of project. Lots of successes so far. VHHA supportive of this project.</p> |
| 11:20 – 12:30N | <p>C. Old Business</p> <ul style="list-style-type: none"> a. CAH screening: 2nd tier screening update: Chris Nixon, DCLS <ul style="list-style-type: none"> i. Main goal: reduce CAH false positives ii. Updates: Optimized DBS extraction procedure, delayed due to accelerated implementation of LSD, will screen 365 days a year. Plan for August 2019 rollout. b. X-ALD & SMA screening implementation update: Jennifer Macdonald, VDH <ul style="list-style-type: none"> i. We are currently in the 30 day public comment for Stage 1. c. CMV screening implementation <ul style="list-style-type: none"> i. We have been tasked by the General Assembly to change the regulations to test all babies for cCMV who fail their hearing screen. Currently in planning stages and establishing a program coordinator. Regulations will have an effective date of September 2020. Virginia will be the first state to utilize their state lab for this testing. d. Expansion to 7 days/week <ul style="list-style-type: none"> i. Data for diagnosed cases from weekend/holiday critical reports presented. Expansion has made an impact in regards to more timely diagnosis. e. DGS NBS Web Portal <ul style="list-style-type: none"> i. Online result retrieval went live May 1st. Portal processes reviewed. Currently working with Department of Health Professions to onboard NPs & midwives. Questions about adding genetic counselors voiced. Users may run into issues w/ border PCPs & military doctors (not in VA database). Working to resolve these issues. Feedback says that the portal seems to have met the needs very well. |
| 12:30 N – 1:00 PM | Break and Lunch |
| 1:00 – 1:30 PM | <p>D. New Business</p> <ul style="list-style-type: none"> a. NBS Fee increase <ul style="list-style-type: none"> i. New fee TBD and working on how that news will be disseminated. Program is actively seeking other funding opportunities to mitigate start-up costs. Questions about how other states pay for NBS voiced. VDH plans on educating legislators on NBS processes. |
| 1:30 PM | Adjournment |

Next meeting dates: November 14th 2019

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