

# Virginia Newborn Screening Advisory Committee

December 9, 2021

9:45 AM – 2:00 PM

## Minutes

**Members (BOLD = present):**

- |   |   |
|---|---|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Dr. Bill Wilson, UVA, Chair</b></li> <li><input type="checkbox"/> <b>Abraham Segres, VHHA</b></li> <li><input type="checkbox"/> Dr. Christina Grant, CNMC;<br/><b>Proxy: Allison Shaw, MSN, CPNP-PC</b></li> <li><input type="checkbox"/> Julie Murphy, Parent</li> <li><input type="checkbox"/> <b>Karen Shirley, HCA-Va, Chippenham Hospital</b></li> <li><input type="checkbox"/> <b>Lisa Shaver, Children’s Hospital of Richmond at VCU</b></li> <li><input type="checkbox"/> <b>Jennifer Lent, Genetic Counselor, VCU</b></li> <li><input type="checkbox"/> Dr. Christian Chisholm, UVA, ACOG</li> <li><input type="checkbox"/> Dr. Jane Die, Virginia Chapter AAP;<br/><b>Proxy: Dr. Barbara Boardman, AAP</b></li> <li><input type="checkbox"/> Dr. Richard Bennett, Community Pediatrician</li> <li><input type="checkbox"/> Dr. Sylvia Lee, Community Pediatrician</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Tiffany Carter, MOD</b></li> <li><input type="checkbox"/> Jana Monaco, NORD, Parent</li> <li><input type="checkbox"/> Dr. Hind Al Saif, VCU</li> <li><input type="checkbox"/> <b>Dr. Samantha Vergano, EVMS/CHKD</b></li> <li><input type="checkbox"/> <b>Dr. Brooke Vergales, Neonatologist, UVA</b></li> <li><input type="checkbox"/> Kim Pekin, CPM</li> <li><input type="checkbox"/> <b>Eileen Coffman, Registered Dietitian</b></li> <li><input type="checkbox"/> <b>Dr. Alicia Prescott, DOD, Portsmouth Naval Medical Center</b></li> <li><input type="checkbox"/> <b>Rebecca White, American College of Nurse Midwives</b></li> <li><input type="checkbox"/> Dr. Marta Biderman Waberski, INOVA</li> </ul> |
|---|---|
- VDH & DCLS Staff**
- Emily Hopkins, DCLS**
  - Mary Lowe, VDH**
- 

10:00am – 10:20am	<ul style="list-style-type: none"> <li>A. Welcome to DCLS: <i>DCLS Leadership</i></li> <li>B. Role Call</li> <li>C. Introductions of Members and Interested Parties</li> <li>D. Review of Agenda</li> <li>E. Travel Reimbursement (members only)</li> </ul>
10:20am – 10:25am	Public Comment: no public comments
10:25am-11:00am	<p>VDH Programmatic Updates</p> <ul style="list-style-type: none"> <li>● NBS/Sickle Cell Program, Shamaree Cromartie:               <ul style="list-style-type: none"> <li>○ Modification to work plan: add requirements related to health equity in collaboration with Child Development Center and Care Connection Center. Marcus Allen is working with epidemiologists staff to support those clinics to look for gaps in regard to race.</li> <li>○ Survey young adults about their thoughts surrounding transitioning from pediatrics to adult care.</li> <li>○ Received 3 of 6 data sources needed to build surveillance system. Will have some new data regarding sickle cell, NBS, how far patients have to travel to care, etc. by start of new year</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>● EHDI/CMV – <a href="#">Deepali Sanghani</a>: <ul style="list-style-type: none"> <li>○ Completed needs assessment (Covid-19 impact on EHDI systems: delays/barriers to services); report completed. Additional funding for changes to address those priority areas granted.</li> <li>○ In Feb 2021, purchased 23 hearing screening equipment for those giving birth outside hospital</li> <li>○ Revised Follow Up text messages: now send short videos for next steps after hearing screening</li> <li>○ Report – 98% babies in VA received preliminary hearing screen at birth; 3700 did not pass; 2042 did not receive, many went back to get outpatient screening; 731 not documented for hearing screening; 133 diagnosed with permanent hearing loss in 2020.</li> <li>○ CMV Screening: opened VISITS to PCP offices</li> <li>○ Developed care process model for positive saliva PCR test. Since Sept. 2020, 4007 babies were screened. 62 were positive for the initial CMV screen</li> </ul> </li> </ul> <p>New collaboration with <i>ASL Connect</i> to provide free ASL lessons to those diagnosed with permanent hearing loss under the age of three</p>
11:00am-11:15am	Break
11:15am – 12:00pm	<ul style="list-style-type: none"> <li>● DBS Follow Up, Mary Lowe: <ul style="list-style-type: none"> <li>○ Added 2 new conditions to NBS panel – XLAD and SMA Discussed that the plan is to start testing for these new conditions by Spring 2022</li> <li>○ Data through 11/20/21 shows that: 7,161 infants were screened; 96,252 samples received; 987 treatment samples; 2,853, 254 tests run; 15,548 abnormal; 1,652 critical; 2,809 diagnosed; 183 lost to follow up; 2.6% unsats</li> <li>○ Showed the Rejection Data Graph (2013 thru 11/30/2021)</li> <li>○ Showed the Quality Indicator Data Graph (2013 thru 11/30/2021) – Time of Collection to Time of Receipt</li> <li>○ Showed Average NBS Transit Times Graph (2021)</li> </ul> </li> <li>● DCLS, Gretchen Cote: <ul style="list-style-type: none"> <li>○ DCLS Connect portal: over 1000 PCPs registered as of 11/30/21</li> <li>○ Upcoming changes: In Q1 2022, DCLS will be updating to NBSVI v2.0. These updates will result in reclassifications. There will be efforts made to report accurately based on these reclassifications. For example, DCLS shall be required to notify all submitters of any changes to a variant’s classification that could have potential clinical significance. The top six reported VOUS will be included in reclassifications. <ul style="list-style-type: none"> <li>■ V2.0 Updates <ul style="list-style-type: none"> <li>● evaluation of variants based on continental population frequency</li> <li>● increase in new assertions due to updates in the data source syncs</li> <li>● addition of ACMG criteria to Variant Reports</li> <li>● Shorter reports with consolidated data</li> </ul> </li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>● Links to some external sites</li> <li>■ Amendment Types <ul style="list-style-type: none"> <li>● Benign</li> <li>● Pathogenic</li> <li>● Reversal of Classification</li> </ul> </li> </ul>
12:00pm-1:00pm	<ul style="list-style-type: none"> <li>● Working Lunch: Electronic NBS Test Orders and Results Messaging, Guest Speaker Willie Andrews <ul style="list-style-type: none"> <li>○ Discussed benefits of implementing e-messaging for NBS</li> <li>○ Update on which of VA's hospitals have completed this implementation</li> <li>○ Discussed current NBS e-messaging grant project</li> <li>○ Shared the challenges around getting project approval from hospital leadership</li> <li>○ Sought advice and assistance of NBS Advisory Committee <ul style="list-style-type: none"> <li>■ help improve communication with hospitals</li> <li>■ get hospital commitments to implement e-messaging for NBS</li> <li>■ need connections and influence and project advisors</li> </ul> </li> </ul> </li> </ul>
1:00pm-2:00pm	<p>Open Discussion/Adjournment, Dr. Bill Wilson GALT Summit</p> <ul style="list-style-type: none"> <li>● June 2019 Genetics Meeting <ul style="list-style-type: none"> <li>○ Consultants requested GALT data to review and to consider changing the following: <ul style="list-style-type: none"> <li>■ 3 X ABN GALT ≠ Critical/Presumptive Positive</li> <li>■ Is a 3<sup>rd</sup> card being received for 2 x ABN GALT- and if TGAL is WNL, is it necessary?</li> <li>■ What are we screening for: Classic Galactosemia ? WNL TGAL on NBS?</li> </ul> </li> <li>○ Follow-Up change: No longer reporting 3x ABN GALT on weekends/holidays/after hours- holding until next business day</li> <li>○ Data Review: <ul style="list-style-type: none"> <li>■ 2 cases with WNL TGAL on first screen were prenatally diagnosed and on soy formula at time of first screen</li> <li>■ No 3x ABN GALT WNL TGAL = Classic Galactosemia diagnoses</li> <li>■ No cases documented of Classic Galactosemia with WNL TGAL on first NBS</li> </ul> </li> <li>○ Lab said cannot release report based on one analyte, entire report needs to go out. If we change to 2 screens, that can be done. Will take time.</li> <li>○ Consultants: No referral needed if &lt; GALT and WNL TGAL, can close case. Need to add standard verbiage regarding non-clinical concerns of GALT on report, and proceed with well child.</li> </ul> </li> </ul>

Next Meeting Date: 6/30/2022