

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*

AGENDA

Members (check = present):

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

VDH & DCLS Staff

- Christen Crews, VDH
- Emily Hopkins, DCLS

9:00 – 9:10	Welcome: Dr. Bill Wilson, Chair A. Role Call of Members and Interested Parties B. Approval of June 18, 2020 Meeting Minutes C. Review of Agenda
9:10 – 9:20	Public Comment
9:20 – 9:30	Parent Perspective: False Positive Experience, Dr. Anna Irwin
9:30 – 9:50	Programmatic Updates: Christen Crews, Emily Hopkins A. Virginia Programmatic Updates a. Sickle Cell Screening Program b. CYSHCN Updates c. EHDI/cCMV d. Birth Defects/CCHD e. Dried Blood Spot B. Electronic Messaging C. DCLS Connect Portal- NBS Results D. NBS Data Review
9:50 – 10:00	New Business A. SMA/X-ALD Implementation Updates, Christen Crews B. LSD Screening Updates, Leigh Emma Lion and Paul Hetterich C. Next Meeting Dates
10:00 – 11:30	Krabbe Disease Review A. Workgroup Presentation, Christen Crews B. Board Member Discussion C. Roll Call Vote D. Next Steps
11:40 – 12:00 PM	Open Discussion/Adjournment