

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"/> Katie Page, American College of Nurse Midwives |
| <input type="checkbox"/> Dr. Richard Bennett, Community Pediatrician | <input type="checkbox"/> Dr. Marta Biderman Waberski, INOVA |
| <input type="checkbox"/> Dr. Sylvia Lee, Community Pediatrician | |

VDH & DCLS Staff

- Christen Crews, VDH
- Emily Hopkins, DCLS

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| 9:00 –9:10 | Welcome: Dr. Bill Wilson, Chair A. Role Call of Voting Members 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. CYSHCN Updates: Marcus Allen, MPH b. VA Sickle Cell Awareness Program: Shamaree Cromatrie, MPH c. EHDI/cCMV: Deepali Sanghani, MPH d. Birth Defects/CCHD: Katherine Crawford, MPH 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- TBD |
| 10:00 – 11:40 | Krabbe Disease Review A. Delegate Jason Miyares, Virginia House of Delegates, 82 nd District B. Workgroup Presentation, Christen Crews C. NBS AC Board Member Discussion, Facilitated by NBS Staff D. Roll Call Vote, Dr. Bill Wilson E. Next Steps, Christen Crews |
| 11:40 – 12:00 PM | Open Discussion/Adjournment |