

Newborn Screening Advisory Committee
Regulation Review Workgroup Meeting
Friday April 22, 2022
1:00pm – 2:00pm

Virtual Meeting

Registration Link: https://vdh.zoom.us/webinar/register/WN_W9qWcmI2Tb6_cmsdc60csw
Note: Workgroup members have been pre-registered as panelists.

Meeting Minutes

Committee Members Present: Abraham Segres, Samantha Vergano, Tiffany Carter
Additional Workgroup Members Present: Brent Rawlings (VHHA), Kim Pekin (CPM)

Virginia Department of Health (VDH) Staff Present: Christen Crews, Mary Lowe, Carli Simpson, Shamaree Cromartie

Division of Consolidated Laboratory Services (DCLS)/Department of General Services (DGS) Staff Present: Leigh Emma Lion (NBS Laboratory Group Manager), Paul Hetterich (NBS Laboratory Group Manager)

After welcoming everyone and introductions, Christen Crews, MSN, RN, Virginia Newborn Screening and Birth Defects Surveillance Programs Manager, reviewed the proposed plan for completing the periodic regulation review of 12VAC5-71. This includes using Microsoft Teams for collaboration/edits outside of workgroup meetings and drafts shared by email to all workgroup members prior to the next workgroup meeting. The proposed edits will be discussed at each scheduled regulation review meeting, and the final edits discussed at the Newborn Screening Advisory Committee meeting for review and vote.

Ms. Crews opened the discussion regarding the distinction and naming of the Virginia Newborn Screening Programs. Historically, the Virginia Newborn Screening Program (VNSP) has been referenced when speaking of newborn screening related to dried bloodspot screenings; however, a larger umbrella falls under VNSP including dried blood spot (DBS), hearing (EHDI), and critical congenital heart disease screening (CCHD). The utilization of VNSP for DBS activities has caused confusion with both external stakeholders. As a result, Ms. Crews asked other states what they referred to their DBS program as for their stakeholders. At the time of the meeting, it was found that the majority used Newborn Bloodspot Screening Program (four states), Newborn Metabolic Screening Program (two states), and Newborn Heel Stick Program (one state). The programmatic staff of the VDH DBS Follow-Up program prefer to use "Newborn Bloodspot Screening Program," as it is a clear association to the screening type and more than metabolic screening is performed. Discussion was had amongst the workgroup members about the necessity for the change, and Mary Lowe, RN, VDH DBS Nurse Supervisor, shared her experiences both in the provider office and with the state program as to the confusion it can cause. The workgroup members agreed to the name change of Virginia Newborn Screening Program to Virginia Newborn Bloodspot Screening Program. This will also affect the naming of the Advisory Committee, if adopted by the Committee.

The workgroup then reviewed the following regulations with the proposed changes:

12VAC5-71-30. Core panel of heritable disorders and genetic diseases.

A. The Virginia Newborn Screening ~~System~~Programs, which includes the Virginia Newborn Bloodspot Screening Program (VNBSP), the Virginia Early Hearing Detection and Intervention Program (EHDI), and the Virginia Critical Congenital Hheart Disease Screening Program (CCHD), shall ensure that the core panel of heritable disorders and genetic diseases for which newborn screening is conducted is consistent with but not necessarily identical to the U.S. Department of Health and Human Services Secretary's Recommended Uniform Screening Panel (RUSP).

~~B. The department shall review, at least biennially, national recommendations and guidelines and may propose changes to the core panel of heritable disorders and genetic diseases for which newborn dried-blood-spot screening tests are conducted.~~

B. The Virginia ~~Genetics~~Newborn Bloodspot Screening Advisory Committee may be consulted and provide advice to the commissioner on proposed changes to the core panel of heritable disorders and genetic diseases for which newborn dried-blood-spot screening tests are conducted.

C. The Newborn Bloodspot Advisory Committee. shall review, at least biennially, modifications to the RUSP and may propose changes to Virginia's core panel of heritable disorders and genetic diseases for which newborn dried-blood-spot screening tests are conducted, to include any NBS designated on the RUSP.

Future discussion: Define process for adding new disorder- workgroup, etc. If there is a disorder proposed outside of the biennial review and not on the RUSP, then will not be considered until on the RUSP.

12VAC5-71-40. Religious exemption from newborn dried-blood-spot screening requirements.

Discussion occurred regarding the statement of "religious practices or tenets" in this regulation. Mr. Brent Rawlings of VHHA will review the language to ensure it conforms to current practices.

At the conclusion of the meeting, Ms. Crews advised she will schedule additional workgroup meetings to continue to review any potential changes needed for the program.