

**Virginia Newborn Screening Advisory Committee**  
**Thursday June 30, 2022**  
**10:00 AM – 2:00 PM**  
**Location: Virtual Meeting via Zoom**

**Minutes**

**Members (Present= Bold):**

- Dr. Bill Wilson, UVA, Chair
- Abraham Segres, VHHA
- Dr. Christina Grant, CNMC
- Julie Murphy, Parent
- Karen Shirley, HCA-Va, Chippenham Hospital
- Lisa Shaver, Children’s Hospital of Richmond at VCU
- Dr. Christian Chisholm, UVA, ACOG
- Dr. Richard Bennett, Community Pediatrician
- Dr. Sylvia Lee, Community Pediatrician
- Jana Monaco, NORD, Parent
- Dr. Hind Al Saif, VCU

- Dr. Samantha Vergano, EVMS/CHKD
- Dr. Brooke Vergales, Neonatologist, UVA
- Kim Pekin, CPM
- Eileen Coffman, Registered Dietitian
- Dr. Marta Biderman Waberski, INOVA
- Tiffany Carter, MOD
- Jennifer Lent, Genetic Counselor
- Dr. Nayef Chahin, Virginia Chapter AAP
- Dr. Alicia Prescott, DOD, Portsmouth Naval Medical Center
- Rebecca White, American College of Nurse Midwives

**VDH and DCLS Staff**

- Christen Crews, VDH
- Emily Hopkins, DCLS

10:00 AM –10:10	<p>Welcome: Dr. Bill Wilson, Chair</p> <ul style="list-style-type: none"> <li>A. Roll Call of Board Members</li> <li>B. Introductions of New Members: Jennifer Lent, new member, genetic counselor at VCU health. Dr. Chahin, CHoR new member. Dr. Prescott, cover for Dr. Smith, airforce neonatologist. Rebecca White, CNM in SW Va.</li> <li>C. Review of Agenda</li> </ul>
10:10 – 10:20	Public Comment: no public comments
10:20 – 10:40	<p>VDH Programmatic Updates</p> <ul style="list-style-type: none"> <li>A. CYSHCN Updates, Marcus Allen: CYSHN mostly funded by Title V. several programs: Care Connection for Children; child development program (diagnosed autism, ADHD, etc); sickle cell program (managed by Shamaree Cromartie); sickle cell – legislative priority of Northam, received ~\$805k for funding for the Sickle cell program, 3 fully executed contracts (VCU, INOVA, and Carilion. One is in negotiations). Care Connection for Children – more focus on diversity. Child development clinic is a big area to implement more diversity. Another focus is geography due to rural areas not having adequate access to services.</li> <li>B. EHDI/CMV, Deepali Sanghani: resources for children and families with children who are DHH. Have iPad’s for families to help improve communication skills. Families interested in iPad’s let Deepali know. ASL Connect classes for free ASL classes. CMV: screening required after September 2021 if they have a failed hearing screen; did overview of screenings between Jan 2021 – Dec 2021. Went into detail on positives, failed screening and CMV results, and other tests performed between Jan 2021 – Dec 2021. 110 children diagnosed with perm hearing loss, majority were negative CMV, very few (4 were positive), the rest were not tested. Dr. Wilson asked a question r/t CMV positives vs. negatives.</li> </ul>

	<p>C. Birth Defects/CCHD, Katherine Crawford: birth defects surveillance – discussed program and gave an update regarding program. CCHD – focus is confirming diagnoses and referring infants to care connection for children. Rare disease council – discussed the council and what will happen since it is brand new. Planned recruitment for more staff, specifically full time for CCHD program and also support for rare disease council.</p>
<p>10:40 – 10:45</p>	<p>Break</p>
<p>10:45 – 11:15</p>	<p>Bloodspot Programmatic Updates</p> <p>A. Follow-Up, Mary Lowe: several brief updates – upcoming rebrand (name and logo for program); explained potential misunderstandings; discussed the reason for rebrand and explained the differences in programs. Updated REDCap and explained the REDCap updates as well as new screenings that are being implemented. Added new hospitals into REDCap and two new NICU groups. Discussed new born samples being collected and hiring; also discussed training and education programs to support pediatric providers across the state. Gave contact information.</p> <p>B. Electronic Messaging Updates, Emily Hopkins/Willie Andrews: began by discussing the electronic texting initiative to move away from paper based processes. Have 19 hospitals that are sending sample info electronically. 54 hospitals that are delivering babies and sending samples via electronically. Most hospitals still not sending electronic samples. Awarded HRSA grant (almost \$1 mil) to partner with software vendor to help with expanding use of application. Hard time getting people to use the program; they get far enough ahead and then the hospitals end up not using the program. Holding programs to promote system. In year 3 of grant and no money has been taken away, and carry over has been taken from year to year. Trying to get hospitals engaged and have financial incentives for hospitals to use electronic system. E-messaging advisory workgroup to meet monthly. Advisory workgroup members are welcoming new people to join. Question from Dr. Tony to inquire other incentives for hospitals: grant provides funding to iConnect to develop software functionality as well as funding for hospitals to implement system. Grant will also pay for first year of the subscription. Dr. Chisholm made comment about the system and will speak with people regarding implementing this system and get financial support for building interface between hospitals and DCLS. Monument pediatrics and Richmond pediatric Center have agreed to be beta sites. Pilot launched by end of summer 2022. Lab web portal has been available for online result retrieval. Over 1,000 PCP’s registered. \$40,000 cost to implement the e-messaging system.</p> <p>C. Data Review, Emily Hopkins: date range will be 1/1/21-5/31/22. Brought on two new disorders and added to test runs. Went through rejection data from 2013 – 5/31/22. Since they added new disorders, more imperative to fill out blood spots. Another focus will be on lowering rejections. Went through and discussed diagnosed cases from 1/1/21 – 5/31/22. Discussed ways to remodel the data presentation. Discussed data for time of collection to time of receipt; some hospitals need to have improved utilization of courier; need to make sure samples are not held onto too long. Most hospitals are doing well in not holding samples but some are</p>

	<p>still holding samples and at some low volume hospitals, some samples are still being significantly delayed. Dr. Wilson asked what the difference is between the hospitals that are doing well vs. hospitals that are not doing well. Contact needs to be made to hospitals that are struggling.</p>
<p>11:15 – 11:30</p>	<p>New Business, Christen Crews and Emily Hopkins</p> <p>A. SMA/X-ALD Implementation Updates: began by discussing lab data. Went over total sample screened (22821 as of 6/14/22, 9 false positives, 0 true positives, false positive rates 0.039%). Went over SMA screening summary. Discussed different assays used (screening and diagnostic). Discussed next steps; continue to monitor results and gather data; evaluate algorithm and cut off changes. Evaluating different assays. Paul to talk about X-ALD – went over screening algorithm; also went over how the assays work and also discussed the different ranges. Went over data for screened samples on the different assays and the ranges that were found for samples taken. went over information for education before implementation. Series of webinars being held. Ongoing educational opportunities on the NBS education website. Variety of classes for professionals and healthcare providers.</p> <p>B. ACHDNC Meeting Updates: responsible for reviewing and nominating for conditions for RUSP. RUSP is list of disorders that are screened at birth with 35 disorders currently on list. Regulations say VA does not have to be consistent but VA is generally consistent. One meeting in Feb and one in May. Committee recommended MPS 2 added. Also, recommended GAMT be added as well. If it is added, there would be up to 2 years to consider reviewing adding disorders to NBS screening panel. Recommend Krabbe disease be reviewed.</p> <p>C. NBS AC Future Meetings: due to COVID, meetings have been virtual. As of July 1, all meetings must be held in person. Meetings rescheduled if quorum is not reached. Will send save the date and members must respond with RSVP for next meeting. Need 11 members physically present for quorum. Question was asked if virtual meetings can be utilized and the statute be amended to include the option for virtual meetings to allow business be held, especially if people from across VA would like to attend. Will need to be changed at the statute level. Discussed going back to normal and getting rid of emergency state being in effect.</p>
<p>11:30 – 12:00 PM</p>	<p>Lunch</p>
<p>12:00 – 1:30</p>	<p>Periodic Regulation Review Workgroup and Next Steps, Christen Crews: overview – discussed periodic regulatory review for NBS and is long overdue. Held series of workgroups starting last August and 3 more times in 2022. Contained VDH and DCLS staff. Discussed regulations reviewed by workgroups. Need to review two specifically for DBS today. Discussed changes that were recommended. Discussed branding changes in the regulatory review. Discussed new changes (made during this current AC Meeting) to the regulatory review. One thing to note is baby’s not being missed. Discussed reporting issues and regulations on training with birth registrars. Questions asked about infants being transferred, and what if parents refused screening. Question if anything about refusal are built into regulations. Scope of NBS program was reviewed during this section of the meeting. Changes previously made were discussed. Changes to responsibilities of metabolic treatment and genetic centers were discussed. Discussed next steps for the regulatory review.</p>

1:30 – 1:55	Open Discussion: no discussion.
1:55 – 2:00	Next Meeting Date and Adjournment; Dr. Bill Wilson, Chair: next date is December 8, 2022. Discussed possibility of hybrid meeting. Save the date has been sent and RSVP's need to be sent in. meeting adjourned at 13:23.

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