**Newborn Screening Funding Model Workgroup Meeting**
Monday July 24, 2023, 10:00 AM – 12:30 PM

**Meeting Location:**
Libbie Mill - Henrico County Public Library- Meeting Room
2100 Libbie Lake East St, Henrico, VA 23230
**In-Person attendance is required for Workgroup Members.**
*Virtual meeting attendance is for the public only*
https://www.zoomgov.com/webinar/register/WN_UhZ4gKe8T-6exviqrdx5CA

**Meeting Minutes**

| **Workgroup Member Attendance** | **Representative Organization** | **Voting Record** Y=Yes, N=No, A=Abstain |
|---|---|---|
| **Bold** = Present, In Person<br>* = Proxy (Name)<br>*Italicized* = Absent<br>[1] = Remote | | Adopt Bylaws |
| Voting Members | | |
| **Denise Toney, PhD** | Division of Consolidated Laboratory Services/Department of General Services (DCLS/DGS) | Y |
| **Vanessa Walker-Harris, MD** | Virginia Department of Health (VDH) | Y |
| **Abraham Segres** | Virginia Hospital and Healthcare Association (VHHA) | Y |
| **Jana Monaco** | Virginia Rare Disease Council (RDC) | Y |
| **Chrissy Owen, CPM** | Virginia Midwife Alliance (VMA) | Y |
| **Lisa Stevens, MD*<br>(Proxy: John Morgan, MD)** | Department of Medical Assistance Services (DMAS) | Y |
| **Julie Murphy** | Parent Advocate | Y |
| *William Wilson, MD* | Newborn Bloodspot Screening Advisory Committee (NBS AC) | |
| *Dr. Nayef Chahin, MD* | Virginia Chapter of the American Academy of Pediatrics (VA AAP) | |
| Support Staff | | |
| **Christen Crews[1]** | Virginia Department of Health (VDH) | |
| **Mary Lowe** | Virginia Department of Health (VDH) | |
| **Parker Brodsky** | Virginia Department of Health (VDH) | |
| **Jennifer Macdonald** | Virginia Department of Health (VDH) | |
| **Emily Hopkins** | Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS) | |
| **Keith Kellam** | Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS) | |
| **Jessica Hendrickson** | Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS) | |
| Consultant | | |
| *Sikha Singh* | Association of Public Health Laboratories (APHL) | |

*Additional in-person attendance: Clair Seckner, VDH; Leigh Emma Lion, DCLS/DGS; Paul Hetterich, DCLS/DGS; Heidi Dix, Virginia Association of Health Plans.*

**Council Business**

- The Co-Chairs called the meeting to order at 10:02 am, conducted roll call, and confirmed a quorum of members assembled at the physical meeting location.
- The Co-Chairs reviewed the draft meeting agenda and draft bylaws.
- The Workgroup then voted to approve the draft bylaws as presented with one addition: *replace "Certified Nurse Midwife" to Certified Professional Midwife (CPM) to Virginia Midwife Alliance member seat.* Abraham Segres motioned to adopt, and Julie Murphy seconded. All members in attendance voted in favor.

**Public Comment**

A public comment period was opened for both remote and in-person attendees. There were no public comments at this Workgroup meeting.

**Workgroup Overview**

Christen Crews, MSN, RN, Newborn Screening and Birth Defects Surveillance Programs Manager, VDH, presented to the Workgroup on the history of HB2224 from the 2023 Virginia General Assembly Session. She described how the bill was introduced to eliminate the newborn screening cost to hospitals, providers, and families (~14 million annual fiscal impact). The substitute bill mandated the establishment of this Workgroup to analyze the Commonwealth's current Newborn Screening Fee-For-Service funding model, evaluate alternative funding models, and prepare a report of alternative funding models to the Governor's office and General Assembly by 12/1/2023 (approximate due date for leadership review 9/15/2023).

She then provided an overview of Virginia's Newborn Screening Programs (VNSP). The VNSP includes newborn bloodspot screening (NBSP), Virginia Early Hearing Detection and Intervention Program (VA EHDI), and the Critical Congenital Heart Disease (CCHD) screening program. The NBSP is funded 100% for laboratory (DCLS/DGS) and follow-up services (VDH) through the fee-for-service funding model. Additionally, targeted congenital cytomegalovirus (CMV) testing is included in the fee structure. Approximately 14 million is budgeted for the program, with about 1.7 million for the VDH follow-up program. The fee for service model collects funds through the purchase of bloodspot collection kits. The current fee is $138 per initial collection, and repeat screens are not charged. The VA EHDI program is funded by a combination of HRSA, CDC, and Title V grants. The CCHD program is funded from Title V grant.

Finally, she presented an overview of the historical funding for the newborn bloodspot screening program (NBSP). From 1963-1992, the program was funded through state general funds. The 1976 National Genetics Services Act assisted with the development of genetic services in Virginia, and in 1978 these moved to "block grants". The Title V block grant has shifted its focus from genetics and now funds a variety of comprehensive maternal, infant, child, and adolescent health programs within the VDH Division of Child and Family Health. The block grant did provide some support for VDH NBSP follow-up services through 2002; however, budget constraints required reallocation of funds.

Dr. Denise Toney shared that the program watches for grant opportunities to decrease the fiscal burden of implementation for new disorders or changes in testing methodology.

**Data Review**

Emily Hopkins, MS, Director of Laboratory Operations, DCLS/DGS, presented National Data on Newborn Screening Funding Models (Data Source: NewSTEPS, Association of Public Health Laboratories (APHL). The first data point compared one screen states (38) and two screen states (12). Virginia is a one screen state. The Workgroup members questioned the difference between one screen and two screen states. The two screen states collect a baseline screen shortly after birth and a repeat newborn screen is recommended for each infant at approximately two weeks of age. The testing algorithms for the two screen states do not screen for all disorders on the first screen and complete the screening on the second newborn screen. In

one screen states, all screening is completed on the first screen unless there is an abnormal result. Clarification was provided from Dr. Toney that although Virginia is a one screen state, 2nd tier analysis is performed (i.e. LSD sequencing, Cystic Fibrosis mutation analysis, 2nd Tier CAH testing) and is built into the fee structure. No additional fees for the 2nd tier testing is passed on to the providers or families.

Of the one screen states, 26 (65%) of states are 100% funded by fee-for-service model. Additional funding includes a combination of fee-for-service and grants (17.5%, seven states), general funds (12.5%, five states), fee-for-service and general funds (2.5%, one state), and D.C. is the only program 100% funded by Title V (2.5%). Dr. John Morgan, DMAS, questioned how fee-for-service funding model is reimbursed. Abraham Segres, VHHA, advised that it can vary by hospital on the reimbursement amount. He said very few insurance companies pay by individual costs (global billing); therefore, the hospital may only be partially reimbursed for the newborn screening fee. Dr. Denise Toney suggested a survey to birth hospitals, and Heidi Dix from the Virginia Association of Health Payors referenced an Act from 2021 to prevent harmful billing practices from being passed on to families and suggested that the Workgroup contact VHI to calculate birthing hospital costs across the Commonwealth.

Data was also shared on a breakdown in Virginia from 2021 births (Source: Natality, CDC Wonder) with comparison of out of hospital births to hospital births and payor.

**Workgroup Discussion**

- Fiscal Impact
  - A discussion regarding newborn screen fees and birth hospital collection occurred. Workgroup members questioned if the fee was included in the global fee for insurance or charged separate to insurances/uninsured. It was discussed that it can vary by hospital and by insurance (or uninsured), and it may be different for smaller operations/hospitals. The program has received some reports of hospital charging for every test on the newborn screen. When this occurs, education is provided to the hospital/family with the correct CPT code (S3620) to utilize for billing of newborn screen (includes bloodspot card and collection). The Workgroup questioned if the global fee reimbursement is the best model to have 100% reimbursement from insurances. One Workgroup member shared that their hospital birth was $49,000 last year (uncomplicated birth, before insurance coverage). An out of hospital birth with a midwife can cost $2,500 to $5,000. Out of hospital births (OOH) and billing typically see midwives as out of network and reimbursement is minimal. Optima does not cover OOH. Medicare and Tricare cover a portion of the NBS fee. Concerns were raised about costs being passed onto families if uninsured.

**Working Lunch: State Review of Alternative Funding Models**

- Arizona Newborn Screening Program was unable to attend to present at this meeting. They will be rescheduled for a future meeting.
- Zachery Leeker, Kansas Newborn Screening Program, discussed the funding model utilized in Kansas and newborn screening is provided at no cost to families. Kansas has a Fund in Code that is funded annually by hospitals/HMOs. The individual amounts are determined by an algorithm based on individual hospital birthrates the previous year. There is a cap for annual spending which has caused barriers as increases have had to be requested annually for the last three years. The moneys in the Fund are split four ways, with NBS is Priority number 3 and it is a 50/50 split between lab and follow-up services, meaning follow-up received 1/8th of the available funds. They defined HMO as Healthcare systems/hospitals that pay up-front but can be by insurers. The state fund is funded direct from hospitals; however, some hospitals get it from insurance providers before passing it into the state fund. Amount paid in is determined by previously mentioned algorithm. The algorithm/formula is written in statue to determine payments each year. This can only be amended by petitioning legislature. Midwives are not held to contributions as average birthrate is <10/year.

- Joe Orsini, New York Newborn Screening Program, presented on their program's funding model that does not charge providers or families. In NY, there is an Insurance Department Account that is paid into every year by insurance companies. The Department of Financial Services allots a portion for the newborn screening program (~14 million a year) and the program supplements with grant funding from CDC, APHL, HRSA, etc. Limitations include fairly flat funding for the last 10 years, very difficult to increase the allotment to meet increasing budget demands resulting from implementation of new screening. Grant funding is often needed and has time limits, so state support is needed for after the grant funding ends for continuation of services. Additionally, NY state mandates have precedence for new funding and this can impact the budget allotment for the program. Positive attributes include no birth hospital book-keeping, not dependent on new legislation to increase funding, can request increased budgets in response to program needs and mandates, and program flexibility with grant funding to enhance programs. Another limitation is that no carryover is allowed, so it's "use or lose" by end of fiscal year, which requires preemptive purchases at start of fiscal year.

**Adjourn**

- The Workgroup summarized the following Action Items/Next Steps:
  - Contact VHI for birthing costs and billing
  - Provide additional information on how insurance is billed by hospitals
  - Reschedule Arizona NBS Program funding model presentation
- As the bylaws were adopted with an electronic meeting policy, the next meeting will be 100% virtual. The Workgroup Members will be polled for potential days.
- The Co-Chairs adjourned the meeting at 12:30 pm.