

Virginia Early Hearing Detection Intervention Advisory Committee Meeting Minutes

Friday, June 2, 2023, 10:00 AM-3:00 PM

In-Person Meeting

**Virginia Hospital and Healthcare Association**

**[4200 Innslake Dr, Glen Allen, VA 23060](#)**

**Meeting called to order at 10:03 AM by Valerie Abbott**

**In attendance:**

**Advisory Members:** Robin Bliven, Tracey Yurechko, Ira Padhye, Wanda Council, Ashleigh Greenwood, Judy Alonzi, Valerie Abbott, Sandra Woodward, Pattie Eitemiller, Christine Eubanks, Kara Norcross, Mona Iskander

**Interested Parties:** Stephanie Wong, Lisa Eickel, Cara Crowe

**VDH Staff:** Christen Crews, Daphne Miller, Noesha Ferrell, Deepali Sanghani, Nikki Van

**ASL Interpretation provided by:** Heather Kubitski and Catherine Clough

**Advisory Committee Business:**

- Introductions/Roll Call
- Review of Agenda
- Approval of February 2023 Meeting Minutes
  - Meeting minutes approved all in attendance in favor
- Travel reimbursement was discussed; advisory members requesting travel reimbursement will be sent travel forms via DocuSign after the meeting.
- Nominations and voting
  - Christine Eubanks motioned to nominate Judy Alonzi as Chair for the EHDI AC. The motion was seconded by Patricia Eitemiller. This nomination was accepted by Judy Alonzi.
  - Judy Alonzi motioned to nominate Robin Bliven. The motion was seconded by Ashleigh Greenwood. This nomination was accepted by Robin Bliven.
  - Ashleigh Greenwood motioned to nominate Lisa Eickel. This motion was seconded by Robin Bliven. Lisa Eickel has accepted the nomination

- Tracey Yurechko motioned to close nominations and Christine Eubanks seconded.
- Recorded Votes:

| <b>Voting Member</b> | <b>Nominated: Judy Alonzi</b>         | <b>Nominated: Robin Bliven</b> | <b>Nominated: Lisa Eickel</b>        |
|----------------------|---------------------------------------|--------------------------------|--------------------------------------|
| Valerie Abbott       | Yes                                   | No                             | Yes                                  |
| Judy Alonzi          | Yes                                   | Yes                            | No                                   |
| Robin Bliven         | Yes                                   | Abstain                        | Yes                                  |
| Wanda Council        | Yes                                   | Yes                            | No                                   |
| Patricia Eitemiller  | Yes                                   | Yes                            | No                                   |
| Christine Eubanks    | Yes                                   | No                             | Yes                                  |
| Ashleigh Greenwood   | Yes                                   | No                             | Yes                                  |
| Mona Iskander        | Yes                                   | No                             | Yes                                  |
| Kara Norcross        | Yes                                   | No                             | Yes                                  |
| Ira Padhye           | Yes                                   | No                             | Yes                                  |
| Sandra Woodward      | Yes                                   | Yes                            | No                                   |
| Tracey Yurechko      | Yes                                   | No                             | Yes                                  |
| Lisa Eickel          | Yes                                   | Yes                            | No                                   |
| <b>Totals:</b>       | <b>Yes: 13</b><br>No: 0<br>Abstain: 0 | Yes: 5<br>No: 7<br>Abstain: 1  | <b>Yes: 8</b><br>No: 5<br>Abstain: 0 |

**Agency Updates:**

**Technical Assistance Center for Children who are Deaf and Hard of Hearing**

**Submitted by:** Tracey Yurechko

**Mission:** The Technical Assistance Center for Children Who Are Deaf and Hard of Hearing is funded by the Virginia Department of Education (VDOE) to provide training and technical assistance in the area of deafness and hearing loss. Assistance is available to local public school systems as well as state-operated programs including early intervention through the Virginia Network of Consultants for Professionals Working with Children Who are Deaf and Hard of Hearing (VNOC) in areas such as identification, assessment (educational, psychological), communication of children across the spectrum of modalities (listening and spoken language, American Sign Language, Signed English, etc.), specific needs of children with amplification including cochlear implants, and instructional strategies.

## Updates:

- Registration for Opening Doors - Unlocking Potential 2023 (June 22-23, 2023) is now open. To register, please visit: <https://event.me/4zzMWP> Early registration closes on June 6, 2023.
- Outreach Services at the Virginia School for the Deaf and the Blind and the Technical Assistance Center for Children Who are Deaf and Hard of Hearing are offering a limited number of scholarships to attend Opening Doors - Unlocking Potential(ODUP) to professionals who are an employee of a Virginia Public School who serves children who are deaf or hard of hearing or parent of a child who is deaf or hard hearing that attends a Virginia Public School. The scholarships will be awarded as reimbursements for the registration cost for ODUP. The deadline for conference registration is June 6, 2023. Please follow the link: [https://docs.google.com/forms/d/e/1FAIpQLScf2Q06XGD-cNG0LfU18IGVJNxp-ynwlvktEDCPI5mbgLPBg/viewform?usp=sf\\_link](https://docs.google.com/forms/d/e/1FAIpQLScf2Q06XGD-cNG0LfU18IGVJNxp-ynwlvktEDCPI5mbgLPBg/viewform?usp=sf_link) for more information on the scholarship and the application form. If you have any questions, please contact Robin Bliven at [robin.bliven@vsdb.k12.va.us](mailto:robin.bliven@vsdb.k12.va.us) or Tracey Yurechko at [yurechko@vcu.edu](mailto:yurechko@vcu.edu) Funding is limited, so apply today.
- Virginia Network of Consultants continues to support school divisions across the Commonwealth. For the 2022-2023 school year, VNOC has supported nine school divisions. Currently, three requests for VNOC services are ready for the 2023-2024 school year.
- If you want to keep up with future events at the TAC-DHH, please complete the following form: <https://airtable.com/shrgJBAmME9gYXjWz> to receive our weekly newsletter.

## **DBHDS/Infant & Toddler Connection of Virginia:**

The DBHDS/Infant & Toddler Connection of Virginia provided no new updates.

## **Newborn Screening (Dried Blood-Spot and CCHD):**

**Provided by:** Mary Lowe

**Mission:** To provide timely reporting of critical screening results to healthcare providers and specialists across the state, as well as case management for timely follow-up and assistance through the diagnostic odyssey for infants identified through newborn bloodspot screening.

## Updates:

- Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) added Mucopolysaccharidosis Type II (MPS-II) to the Recommended Uniform Screening Panel (RUSP) in 2022.
  - NBS-DBS will be assembling a workgroup to review screening for MPS-II in order to determine if this will be added to Virginia's NBS-DBS panel
  - We are recruiting! We recently welcomed a new senior nurse and a new admin to our team. We will soon be recruiting for:
    - One part-time / wage Short-Term Follow-Up nurse

**University of Virginia Hearing Aid Loan Bank:**

**Provided by:** Sandra Woodward/Vertie Wade

**Mission:** To provide loaner hearing aids/FM systems for a period of 6 months – 1 year to infants and young children following a diagnosis of hearing loss while families secure funding for permanent aids.

**Updates:** Since program begin in 2005, loaned 1552 aids. Over the past few years, 3 other states have contact VAHALB about establishing Hearing Aid Loan programs in their state.

**VDH Children and Youth with Special Health Care Needs (CYSHCN):**

**Submitted by:** Marcus Allen

**Updates:** The CYSHCN program is working with epidemiology staff to wrap up a report on data from a transition survey that we did last year. The survey targeted youth and their families transitioning to adult life and healthcare. We hope to be able to post the results, on our websites, in the coming months.

**Center for Family Involvement @ VCU-Family to Family**

**Submitted by:** Irene Schmalz

**Updates:**

- The Center for Family Involvement @ VCU Family provided family to family support with four families that were referred by the EHDI program to the 1-3-6 Family Educators and information collected from the 1-3-6 Family Educators matched with the families were entered into VISITS shared plan of care.
- 1-3-6 Family Educator updates:
  - A virtual meeting was held on May 31, 2023 with the 1-3-6 Family Educators. Information discussed included family to family support, product development (social media, print, videos, Spanish ads) and working on revising both the Resource Guide and ASL brochure.
  - The VA Families of Children with Hearing Loss Closed Facebook group has 116 members
  - On May 4, 2023, the Center for Family Involvement was one of the 7 agencies represented at the Virginia Supplemental Early Language Resources for Deafness/Hard of Hearing Project Advisory Committee Meeting. The blue and orange Virginia Resource Guides for Families of Children with Hearing Loss

were discussed as a possible resource which would include the updated language assessment information.

- The Opening Doors Unlocking Potential Conference will be held on June 22 and June 23, 2023.
- Family Materials:
  - Postcard about “If your baby did not pass the hearing screening” has been completed. It has both QR codes and links for social media, connect, information, video library. Questions: Please contact Irene Schmalz at [ischmalz@vcu.edu](mailto:ischmalz@vcu.edu)

### **Virginia School for the Deaf and the Blind (VSDB):**

**Submitted by:** Lindsey Richard

**Updates:** VSDB's Outreach and Audiology programs have begun a partnership with the Lion's Clubs of Virginia. Lindsey Richard, VSDB's Audiologist, joined Valerie Abbott, Co-Founder of the National Late Onset Hearing Loss Awareness Campaign, to give a presentation on late onset hearing loss and otoacoustic emissions at the Virginia Lions Club's Annual Conference in April.

Trainings on otoacoustic emissions (OAEs) will be offered to members of the Virginia Lions Club. VSDB will be hosting these on their campus in Staunton, and will offer the first training this summer. The Lions Club members are currently trained on hearing screenings. We are now hoping to add OAEs to their test battery. OAEs will allow them to expand their test services to younger children who are unable to respond to the hearing screenings.

- Science of Reading for students with sensory disabilities training planned throughout the next school year.
- Fingerspelling Your Way to Reading training continues – four trainings were done in 2022 and will roll into 2023.
- Classroom Listening Assessment training Fall 2023
- Virtual Professional Resource Fair September 2023 on Zoom with Breakout Rooms
- Joint project with Hands and Voices, TACDHH, and DARS to allow children of a variety of ages to join and communicate and share resources while completing a craft.

### **Virginia Department of Education**

**Submitted by:** Wanda Council

**Mission:** The mission of the Virginia Department of Education (VDOE) is to advance equitable and innovative learning

**Updates:** The Virginia Supplemental Early Language and Literacy Resources for Deafness/Hard of Hearing (VA SELLR-DHH) Project Advisory Committee held the final advisory

committee meeting in-person on May 4, 2023, at the Virginia Hospital and Healthcare Association Conference Center in Glen Allen, Virginia. Pursuant to § 22.1-217.04, the Virginia Department of Education, in coordination with the Department for the Deaf and Hard of Hearing and the Department of Behavioral Health and Developmental Services, established an advisory committee for the purpose of soliciting input from members on the selection of language developmental milestones for inclusion in a resource for use by the parents of a child from birth to age five who is identified as deaf or hard of hearing. Subsequently, parents may utilize the information to assist with monitoring and tracking their child's expressive and receptive language acquisition and developmental stages toward English literacy. The advisory committee members also provided recommendations for language assessment and evaluation tools for professionals to use with children who are deaf and hard of hearing.

Information pertaining to the VA SELLR-DHH advisory committee meetings can be found at the Virginia Regulatory Town Hall and the VDOE websites.

### **Virginia Project for Children and Youth with Deaf-Blindness:**

**Submitted by:** Ira Padhye

**Mission:** The Virginia Project for Children and Young Adults with Deaf-Blindness (VDBP) is committed to supporting families, teachers, and service providers in their endeavors to improve outcomes for children and youth who experience both vision and hearing loss. Through providing technical assistance, training, and information, we aspire to improve the quality of life for people with deaf-blindness as they live in their homes, learn in their schools, socialize in their communities and access the services they choose.

### **Updates:**

- The Virginia Deafblind Project submitted our Child Count at the beginning of May. We had 33 newly identified students (birth to 22) and of those 4 were birth to 2 years old.
- We are offering mini grants for families to attend the national CHARGE Syndrome Conference July 20th- 23rd in Orlando, FL.
- On May 16th, we hosted an online Intervener Q&A for families, educators (including paraprofessionals interested in receiving training), administrators in order to share information on some frequently asked questions on the role, training options, resources to support teams getting an intervener on the child's IEP.
- June 30th - July 2nd, the Deafblind Project is hosting a Transition Retreat for middle school and high school aged students who are deafblind and their families. The purpose of the retreat is to support these students as they plan for life after school. We have 6 families registered and registration is closed. But, we are having an "Agency Show and

Tell" so if you are interested sharing information or volunteering with families and young adults, please reach out to us.

**Virginia Department for the Deaf and Hard of Hearing (VDDHH):**

**Submitted by:** Eric Raff

**Updates:**

**Executive Management**

2023 General Assembly - During the 2023 Session of the General Assembly, §§ 8.01-384.1 and 19.2-164.1 of the Code of Virginia were amended and reenacted as follows (changes in italics): "...Interpreters for the deaf and hard of hearing in these proceedings shall be procured through the Department for the Deaf and Hard-of-Hearing; *if the Department cannot procure such services, then the court may appoint a readily available interpreter with full certification from the Registry of Interpreters for the Deaf, Inc., or an equivalent national certification. Such court appointed interpreter's qualifications are subject to review and approval by the Department for the Deaf and Hard-of-Hearing...*" Prior code stipulated that only VDDHH would identify a particular qualified interpreter for a given request, and VDDHH stood firm that the amended bill should preserve VDDHH's ability to vet and approve interpreters found by the court so as to minimize the risk of harm to the community. The amended Code can be found at <https://lis.virginia.gov/cgi-bin/legp604.exe?231+ful+CHAP0415+pdf>

Statewide Interagency Team (SIT) – SIT comprises of four agencies, the VDDHH, the Department of Aging and Rehabilitative Services (DARS), the Department for the Blind and Vision Impaired (DBVI) and the Valley Community Service Board. SIT members have not met however a draft of the needs assessment report was circulated for comments and feedback.

VDDHH Advisory Board – The Advisory Board met on Wednesday February 1 at the VDDHH conference room. HHR Secretary John Littel attended to meet with the Board members and to give remarks. The Board received program managers' and board members' reports. The Board received the draft "Smart Device App Guide" publication and provided feedback. Rhonda Jeter gave an update on the status of the FY23 budget and Director Raff provided information about 2023 legislative bills impacting deaf and hard of hearing people.

Human Resources – We continue to recruit for the Administrative Assistant position. Karen Rhoads started working on February 10 as the D/HH Regional Specialist for the Fredericksburg region. Sharon Ellis Sandoval started working on January 25 as the Deaf Mentor Coordinator VDDHH will be recruiting for a part-time Support Service Provider Coordinator position and a full-time Policy Analyst position.

Ratcliff Building - Facility Management – VDDHH met with DARS facility management to receive updates that the planned renovations of the DARS and VDDHH central office will not proceed. Department of General Services (DGS) had instructed DARS to develop a Request for Proposal (RFP) to secure a new lease with the possibility at a new facility and may require relocation. VDDHH staff met with DARS to discuss spacing needs and location requirements. A new lease would be effective January 2025.

The Virginia Higher Education Accessibility Partners (VHEAP) - The VHEAP Captioning Work Group had successfully awarded eight (8) contracts for captioning services including postproduction captioning, live captioning, remote captioning, audio description (for the blind). The vendors met with the VHEAP committee to demonstrate their services and answer questions. The website lists the 8 vendors offering the various types of services <https://vheap.org/vheap-captioning-initiative/> The vendors submitted their first quarterly report.

HB649-SB265 relating to Language Milestones & Assessments of D/HH - Virginia Department of Education (VDOE) is the lead agency and established an advisory committee, “Virginia Supplemental Early Language and Literary Resources for Deafness and Hard of Hearing (VA SELLR-DHH)” to identify language milestones as a resource for parents and language assessments as resource for professionals. VDDHH (Eric Raff, Director) and Department for Behavioral Health and Developmental Services (DBHDS) (Teri Nelligan, Infant-Toddler Connection early intervention) is to advise and consult with VDOE (Wanda Council), supporting this initiative. VA SELLR-DHH is tasked to identify, review and recommend the milestones and assessments to the three agencies. The second meeting was held Friday February 3 and third meeting was held on Friday March 10.

Office of Governor and Health and Human Resources Secretariat – Governor Glenn Youngkin and First Lady, Suzanne Youngkin along with HHR Secretary John Littel, Deputy Secretary Leah Mills, Policy Analyst Calvin Hoggs visited VDDHH central office on Tuesday March 14. Director Raff gave the entourage a tour of VDDHH historical memorabilia and display of antiquated assistive technology. Afterwards, the entourage met with the VDDHH management team for a briefing on each of the programs and services offered by VDDHH with a Q & A session. It was the first time in VDDHH history that a sitting Governor has visited the VDDHH central office.

Credentialing Interpreters in Legal Settings – In consultation with Star Grieser, Registry of Interpreters for the Deaf (RID) CEO and Bob Lichtenberg, Washington State Administrator of the Courts Interpreter Coordinator, Director Raff established a workgroup to explore the feasibility of obtaining funding and conducting testing development to reinstate the SC: L certification which underwent a moratorium in 2016. The first meeting was on March 31 and



included Howard Rosenblum, National Association of the Deaf (NAD) CEO, several SC: L certified interpreters, Shane Feldman, Innivee CEO, and Karen Brimm, Interpreter Services Manager.

## **Virginia Relay**

Virginia Relay Outreach Coordinator – After serving 5 ½ years in Virginia, Eric Alvillar accepted a transfer opportunity to become the outreach coordinator in California to be closer to his family in Arizona. VDDHH staff hosted a farewell dinner with Mr. Alvillar on Wednesday February 8. Hamilton Telecommunications, Inc. was recruiting for a replacement.

Virginia Relay Advisory Council (VRAC) – VDDHH has been recruiting for four (4) vacant VRAC seats available:

1. Speech and Hearing Association of Virginia (SHAV)
2. Voice Carry-Over Relay User
3. Captioned Telephone Service Relay User
4. Internet/Wireless Relay User

Due to not being able to fill these vacancies, we have decided to disband VRAC. As an alternative to this council, we will start working on hosting quarterly virtual meetings for the purpose of ensuring that the needs and concerns of relay users across the Commonwealth are being addressed.

Digital Equity Act and Affordable Connectivity Program (ACP) - Since learning that we are unable to share Technology Assistance Program consumer information with the Department of Housing and Community Development (DHCD), there was no additional communication or correspondence with DHCD during Q3 however VDDHH continue to be interested in this partnership. During Q3 we did develop and print ACP postcards that will be sent to Relay users who have received equipment through our Technology Assistance Program that provide an overview of the Digital Equity Act as well as information about ACP. We plan on mailing these postcards out during Q4.

## **Technology Assistance Program (TAP)**

Online TAP Application - We are working to make the TAP application process available online for consumers. We met with IT to discuss the feasibility, potential security risks, security measures that can be implemented to safeguard the consumers information and how the online application can be routed to the appropriate Specialist.

Tablets – In the previous quarterly report, we were planning to add tablets into the TAP program by the third quarter of FY23. However, we learned that there is Federal program

available which provides individuals with a tablet for \$10.99 and free internet services. This program is called the 360 Connect. At this time, we are working on deciding if we should duplicate efforts and add tablets to TAP to provide free tablets to those who qualify for our free equipment, or if we should shift, use our funds for digital equipment and refer applicants to the 360 Connect for tablets.

Guide to Apps - At the request of the VDDHH Advisory Board, the TAP has developed a list of apps individuals can download for communication access. VDDHH obtained feedback from the staff, D/HH Regional Specialists, and the VDDHH Advisory Board. The Advisory Board had recommended adding photos. The final draft will be reviewed and released to the public soon.

### **Interpreter Services Program (ISP)**

Promoting Equity in Healthcare Interpreting (PEHI) – VDDHH is continuing to participate in the Promoting Equity in Healthcare Interpreting (<https://www.isu.edu/pehi/>) project. PEHI is funded by a 5-year federal Rehabilitation Services Administration (RSA) grant and is conducted by Idaho State University and Gallaudet University in partnership. VDDHH is one of several partnering state agencies (PSAs) collaborating to provide training and expand the pool of sign language interpreters in healthcare settings. Several sign language interpreters from Virginia were selected to be in the first cohort for training. VDDHH took some action steps to create mentorship opportunities for them in healthcare settings.

### **Virginia Quality Assurance Screening (VQAS)**

Educational Interpreter Performance Assessment (EIPA) - Relaunched the availability of the EIPA. The first Performance and Written Assessments were successfully proctored. This offering had been on hold since 2020 due to hiatus during COVID-19 closures, retirement of authorized proctor, and the need for redesign of the interpreter assessment registration system (IARS). Both Manager and Coordinator are now authorized proctors, and the IARS continues to be refined.

Virginia Department of Education Grant - Received formal approval of the federal FY23 grant application for Virginia Department of Education funding in support of the VQAS program. This funding continues to be level set at \$65,793.00 for activities occurring October 2022 – September 2023. We also continue participation in quarterly VDOE Grant Coordinator meetings.

### **Community Services**

Support Service Provider (SSP) Pilot Project - Lynn Odom, Community Services Manager. Lynn has been meeting with Reynolds Community College to plan and develop a curriculum. The

SSP stakeholder workgroup comprising of various organization representatives met on March 16th to review policies and procedures and the SSP Coordinator job description.

Deaf Mentor Project – Sharon Ellis Sandoval started working as the Deaf Mentor Coordinator on January 25. 13 deaf adults were initially selected to become Deaf Mentors, but one had withdrawn, leaving 12 remaining. The 12 Deaf Mentors came to Richmond to attend the SKI-HI Institute curriculum training led by two of the Institutes’ leaders. The SKI-HI 3-day training session was held at VDDHH conference room on February 10-12, 2022. VDDHH also is exploring the feasibility of having the Deaf Mentor families attend the American Society for Deaf Children conference being held in Williamsburg, VA this June.

### **Virginia Hands & Voices:**

**Submitted by:** Terese Urban

**Mission:** Virginia Hands & Voices is a non-profit, 501(c)(3), parent-driven organization. We are dedicated to supporting families with children who are deaf and hard-of-hearing without bias around communication modes or methodology. Virginia Hands & Voices provides parents with the resources, networks, and information they need to improve communication access and educational outcomes for their children.

### **Updates:**

Virginia Hands & Voices has been busy supporting families throughout the Commonwealth. We hosted six events this past quarter:

- Virtual Roundtable Discussion with DHH Adults
- Evening social at Twisted Track Brewpub in Roanoke
- Exhibited at Fairfax County Public Schools DHH Connections Picnic
- Attended the Flying Squirrels 2nd Annual Disability Awareness Day in Richmond
- ‘Pizza in the Park’ at Chessie Backyard in Franconia
- Virtual presentation with DARS - ‘Beyond High School: Transition Services for DHH Children’

Looking ahead at our summer calendar:

- Hosting ‘Pastries, Performances and Playgrounds’ (OH MY!) in Alexandria, June 17
- Exhibitor, presenter and planning team member at Opening Doors Unlocking Potential conference in Richmond

We received four requests for family mentoring which were conducted over Zoom with Virginia Hands & Voices Board members.

Carlie Smith, our Membership Chair and board member since 2019 resigned to focus on her growing and very active daughter. We can never thank her enough for her dedication to our chapter the past four years and for being a strong support to families in the Roanoke area. Her role was filled by Emilie Mulholland and we are excited to see her grow in this position. We also welcomed Dr. Karen Woolman to our board of directors this past quarter. She has the experience growing up with a deaf sister and is a pediatric audiologist at Children's National Hospital at the Northern Virginia Regional Outpatient Center. We love the energy and perspective Karen has brought to our board.

### **Parent Perspective**

- A parent, C. Crowe, shared her family's journey with the VA EHDI AC on the diagnosis of congenital Cytomegalovirus (cCMV) of her second child. She found she was pregnant with her son in June 2020 and their daughter who was 17 months old at the time went back into daycare in October 2020. Crowe went to all routine OB checks did not experience any abnormal symptoms during her pregnancy. Crowe mentioned that due to a failed hearing screen at birth and the newly passed legislation for targeted cCMV screening in Virginia, her son was diagnosed with cCMV soon after birth and later identified to have a hearing loss. Crowe discussed the fear of the unknown possibilities soon after diagnosis. She felt very alone, with little support from health professionals and no one could give her a clear answer. Crowe wished that health professionals informed her about CMV during her pregnancy- she is continuously advocating for CMV awareness since.

### **EHDI Updates provided by Daphne Miller and Deepali Sanghani**

- The VA EHDI Website Analytics were shared as below:
  - The webpage views for the VA EHDI website from July 1, 2022 to May 22, 2023 had a total of 20,303 views.
  - The material downloads from July 1, 2022 to May 22, 2023 had a total of 2,601 downloads.
- Grant Updates were shared as below:
  - The next HRSA funding will be out August 2023.
  - The EHDI team is preparing to do a performance report that will be due July 2023.
  - They are continuing to work on an evaluation for the CDC that is due in September 2023.
  - They are continuing to work on report card to be sent hospitals on CMV.
  - An enhanced VISITS system will be implemented with a call dashboard to facilitate follow-up staff with locating infants.
  - The EHDI team will focus on communicating to parents and providers/PCPs electronically – by text messages and emails – to reduce costs of mailing letters.

- The EHDI team submitted an application for a CMV CDC grant.
- VA EHDI Team Updates
  - A Technical Assistant position was filled by Nikki Van in May 2023.
  - The EHDI team has Summer 2023 intern positions has been filled with Jonathan Duong and Aisha Khalifa.
  - The HRSA Specialist and Follow-up Specialist positions are currently vacant.
- The “Preparing for the Birth of Your Baby” Brochure with QR codes are completed and will be sent to hospitals.
- Expansion of EHDI follow-up to 36 months
  - They will push to expand screening for children who are born outside the hospital. Along with addressing gaps in follow-up by evaluating regions that are affected by loss of follow-up. There will also be efforts to increase prenatal education on hearing screenings and early intervention.
- PCP Outreach
  - Interns will develop a flyer to send in the mail to spread awareness to PCPs on the importance of VISITS Access.
- Automated EHDI follow-up
  - Outgoing calls in VISITS will be recorded and direct texting implemented into VISITS. There will also be VISITS dashboard to facilitate follow-up.
- Impacts to EHDI follow-up
  - Improved efficiency and timeliness
  - Ability to capture real-time conversations
  - Maintain continuity of follow-up
- In 2021, Virginia had a 97.7% screening rate.
- More thorough follow-up has been done on children who were lost to follow-up since 2021.
- Programmatic Updates Deaf and/or Hard of Hearing
  - VA EHDI iPad Program has distributed 92 iPads to date.
    - For more info, visit the EHDI website under the Events tab
    - Contact [va\\_ehdi@vdh.virginia.gov](mailto:va_ehdi@vdh.virginia.gov)

**The meeting adjourned for lunch at 12:03 PM**

**Public Comment**

- The floor was opened for public comment at 1:15pm, however, there was no public comment

**National CMV Foundation (NCMVF)- L. Eickel**

- Virginia Strides 4 CMV 5k will be held in Ashburn, VA on Saturday June 24, 2023
- June is CMV Awareness Month

- Lisa Eickel of the National CMV Foundation explained impacts of CMV as below:
  - The U.S. spent 1.9 billion annually to treat children with CMV in 1990s
  - Black and multi-racial infants are at increased risk for CMV – some studies report Black infants have an infection rate that is twice as high compared to the rest of the infant population.
- Eickel proceeded to discuss current vaccine development for CMV:
  - Vaccines have been in development for over 30 years – several CMV vaccines have been developed by pharmaceutical companies over the years, but none have succeeded in the clinic.
  - The Institute of Medicine gave development of a CMV vaccine “highest priority.”
- The National CMV Foundation’s mission: To prevent pregnancy loss, childhood death, and disability due to cCMV
  - This mission will be achieved by supporting science-based interventions such as CMV vaccine development, risk-reduction precautions, newborn CMV screening, and investigational treatments during pregnancy.
- The NCMVF strategic goals include: to raise awareness of CMV through advocacy, accelerate mission driven research by funding high impact research aiming to reduce the impact of CMV, target education programs, grow research, and demonstrate their commitment to diversity, equity, and inclusion by having more inclusive education materials for all communities.
- NCMVF Key Programs:
  - The NCMVF established a CMV community alliance that is on their 4<sup>th</sup> year of the ambassador program that empowers CMV advocates to increase CMV awareness in their communities.
  - Education and research
    - Educational materials are available in more than 15 different languages focused on educating target audiences. Some educational materials are available for ordering on the NCMVF website.
- Minnesota is the first state to universally screen infants for CMV.
- The CMV Conference will be held in Salt Lake City, Utah on October 8-10, 2023.
- CMV Awareness and Education Activities
  - The NCMVF has partner organizations that ask for parents’ stories on their experience with CMV
  - There are educational webinars, podcast episodes, blog postings, and other activities to increase CMV awareness.
- NCMVF activities and events:
  - Compete 4 CMV is a Marathon held in New York City. They are on their fifth year as a charity partner with five dedicated runners. During CMV awareness month, Strides 4 CMV events raised more than 35k.

- Faces of CMV is a project where parents send in a photo of their baby that has been diagnosed with CMV and their story. In 2022, there were 112 submissions during CMV Awareness Month
- Communication channels
  - The CMV Speaks Podcast has more than 2,800 downloads.
  - Since 2015, there are blog postings that highlight CMV parents/advocates lived experiences.
  - Newsroom articles highlight recent medical and scientific trends and advancements.
  - Social media channels have more than 20,000 followers.
- Successes to Date
  - The NCMVF has updated their organizational mission and developed a 3 year strategic plan for 2021-2024
  - Their staff has grown to three full-time and three independent contractors
  - A seven member Associate Board was established in 2021 and an internship program was developed
- For more information:
  - [www.nationalcmv.org](http://www.nationalcmv.org)
  - Lisa Eickel ([nationalcmvva@gmail.com](mailto:nationalcmvva@gmail.com))
  - General inquiries ([info@nationalcmv.org](mailto:info@nationalcmv.org))
  - Program inquiries ([amanda.devereaux@nationalcmv.org](mailto:amanda.devereaux@nationalcmv.org))
  - Partnerships and Strategic Planning Inquiries ([khaliah.fleming@nationalcmv.org](mailto:khaliah.fleming@nationalcmv.org))
  - Social Media (Facebook, Instagram, Twitter) - NationalCMV

### **CMV Data**

- Targeted CMV screening implemented September 2020.
- Further into 2022, there is a 90 percentile screening rate for children who failed screenings and received a CMV test.
- If a saliva is positive, then a urine sample is collected for confirmation. The EHDI team is continuously educating hospitals on collecting the initial test properly
- In 2021, 38 babies were initially positive but five were confirmed for hearing loss.
- In 2022, eight babies were detected for CMV on confirmation with only one baby that had true hearing loss
- The EHDI team discussed common sample collection issues from January 2023 to May 2023 as below:
  - 23 CMV tests were not submitted in VISITS.
  - There are 12 sample discrepancies that include missing MRNs or personal information errors.
  - There has also been 60 CMV test rejections.

- Hospitals are contacted on CMV rejection and the EHDI team conducts site visits to ensure proper protocol is followed and thorough education is provided for hospitals with the most issues.

### **CMV Next Steps**

- The EHDI team shared updates to CMV Screening as below:
  - They are reviewing updated CMV testing options that have been researched and looking at other options for initial testing, which may change.
  - CSTE Position Statement
    - The case definition for cCMV was submitted in March 2023.
- Notice of funding opportunity: CDC-RFA-DD-23-0003
  - This opportunity will allow the tracking of long term CMV disease and treatment outcomes such as the age of treatment onset, side effects from treatment, impacts/benefits of treatment, and the timeliness and accuracy of identifying CMV cases.
  - There will also be a development of a key stakeholder work group along composing materials and information for pregnant women. These upcoming developments will promote and support the increase in prenatal awareness and education.
  - The application for this funding opportunity was submitted in April 2023 and the EHDI team should be notified by August 2023 if funding is accepted.

### **Next Steps**

The next meeting is scheduled for September 15, 2023.

### **Adjournment**

The meeting was adjourned at 2:24 PM