

Virginia EHDI Program Advisory Committee Meeting

Friday, June 4, 2021

Meeting Minutes

Attendees: Debi Leekoff, Kara Norcross, Alison King, Ashleigh Greenwood, Christine Eubanks, Irene Schmalz, Nancy Bond, Patty Eitemiller, Teri Urban, Terri Nelligan, Valerie Abbott, Wanda Council, Eric Raff

Interested Parties: Rebecca Levorson, Alicia Rodriguez, Anne Dare, Catherine Hancock, Ira Padhye, Karen Brimm, Kristie Burnette, Lizzy Allen, Parker Brodsky, Paul Hetterich, Seb Prohn, Sil Thorpe, Stephanie Moody Antonio, Tracy Yurechko, Tom Dowling, Laura Sullivan, Lindsay Richardson, Leigh Emma Lion, Lizzy Allen,

VDH EHDI Staff In Attendance: Jessica Nelson, John Rogan, Jennifer MacDonald, Rafael Randolph, Deepali Sanghani, Antoinette Vaughan, Malik Railey, Christen Crews, Robin Buskey

The meeting was called to order by Ashleigh Greenwood at 9:00am. A review of the agenda was presented and approved. Minutes of the December 4, 2020 meeting were approved.

Implementation of CMV in Virginia:

CVM testing started on September 1, 2020. The cost of the testing is approximately \$60 and is spread across all of the collection places. This equals out to about \$2 per baby.

The testing platform is FDA cleared assay. Collection is a saliva swab that needs to be kept cold and should be done 1 hour after breastfeeding.

- 65,183 cCMV screenings completed from 9/1/20 – 5/19/21.
- 1907 cCMV screens submitted
- 52 positive
- 37 passed
- 34 false positives
- 4 diagnosed with SNHL
- 2 diagnosed with other hearing loss
- 2 inconclusive
- 137 rejected

CMV Discussion:

An open Q&A session was held where participants had the opportunity to discuss the implementation of cCMV screening in Virginia and ask the Panel members questions. Questions included specifics on how PCP's are provided cCMV results, when PCPs would be able to access results from the Virginia Infant Screening Infant Tracking System (VISITS) directly, and who the best point of contact would be for questions for PCPs. Additional discussion points addressed the testing parameters and false positivity rates.

VA EHDI Updates:

- EHDI Annual Meeting 2021- March 1-5, 2021 Virtual
- Parent Professional Collaborative- with Care Project
 - March 18 and 19, 2021
 - Around 35-40 participants each day.
- Virtual EHDI Stakeholders Meeting, April 15, 2021.
- Virginia Society of Otolaryngology Virtual Meeting, April 24, 2021
- Opening Doors Unlocking Potential, June 23-25, 2021

Hearing Screening Equipment Loaner Program

- 13 Midwifery facilities were given OAE testing equipment to provide hearing screenings for newborns
- 12/13 Facilities have begun testing

ASL Connect

- Spring Session - March 21, 2021 to May 15, 2021. 15 families in attendance.
- Summer Session- May 30th, 2021 to July 24th, 2021. 12 families signed up so far.
- Families can sign up for a session by contacting va_ehdi@vdh.virginia.gov

iPads

- Secured iPads for families to use for ASL connect and EI services as needed.

Virginia EHDI Learning Community Updates

- Statewide Learning Community – Tentatively planning for Fall of 2021
- Northern Virginia LC meeting April 21, 2021
- Hampton Roads LC meeting March 31, 2021

Public Comment:

Parent Laura Sullivan voiced a concerned. The cCMV process did not go well for her family. Beginning with the cheek swab she was not told her baby should be fed an hour before the screening. Mrs. Sullivan felt better communication was needed. She felt she was not given enough information. She received 2 phone calls saying her baby's screen was negative but it was not, it was positive, and she felt robbed of 10 days because of this. Dr. Levorson was the only person who gave her good information.

COVID Needs Assessment:

Virtual Event held in February 2021 hosted by VA EHDI & CFI: Impacts of CoVID-19 on EDHI.

- 66 registered
- 47 attended

An overview of the Needs Assessment findings were shared with the meeting participants. The final report is available on the website for review.

Meeting adjourned at 11:44 am.

Padapillo Book Discussion

Valerie Abbott has released a book entitled "Padpillo". The book is based on her daughter Bridget who was identified with a hearing loss at the age of 2. Her older sibling narrates the story. Little Bridget is acting strangely and no one seems to notice except her older sister. When the rest of her family finally realize that Bridget has been ignoring the world around her and inventing weird words, it leads to a startling diagnosis no one saw coming.

The book has received stellar reviews and a terrific tool to help families understand the real-life emotional process family members often experience when a young child is unexpectedly diagnosed with hearing loss. The book can be found in at all major carriers.