Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee

August 18, 2021

Minutes prepared by: Melissa Marsh & Jenna Laine
Location: Virtual

Attendance

Present:

Abby Meyer, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Elizabeth Pai, Gloria Nathanson, Danelle Gournaris, Hannah Herd, Ingrid Aasan, Colleen Ireland, Jesi Novak, Kathy Anderson, Katie Warne, Laura Godfrey, Joscelyn Martin, Renae Allen, Sara Oberg, Terry Wilding, Tina Huang, Jay Wyant

Meeting Minutes:

- **Approval of Minutes**
  - Kathy Anderson - correction/clarification to the May meeting minutes under the Screening up to Age 3 Discussions re OAE in the schools. *Kathy Anderson-- In school districts- it is hearing screening for eligibility evaluations. Under IDEA it is required to assess hearing and vision status. Results are stored in child's assessment files and kept by the district.*
    - Clarification/correction: IDEA does not require school districts to medically "assess" hearing and vision status. IDEA Part C requires districts and teams to "address/document" hearing and vision status under health and physical development. We have encouraged district teams to utilize OAE screening as one way to help the teams more objectively "document hearing status" for all young children (a) referred for eligibility evaluations and (b) for those receiving Part C or Preschool Special Education services. OAEs would be used instead of simply asking parents if the child passed newborn hearing screening and if they have any concerns about their child's hearing. If there were concerns noted by the district teams through use of OAE screening, children would still need to be seen for more clinical evaluation by medical/audiological professionals for the district to then accurately "document the child's hearing status".
  - Minutes from previous meeting approved with correction/clarification stated above.

MDH Legislative Updates – Nicole Brown, MDH

MDH Newborn Screening Fee increase of $42 was approved during this last legislative session. The Vivian Act was included in the Health and Human Services omnibus bill. It includes funding for education and outreach as well as the requirement for the Newborn Screening Advisory Committee to

review CMV for potential addition to the screening panel. If CMV is added to the newborn screening panel, the funding has been secured for the screening.

CMV Overview & MN Study MDH NBS Nomination Process - Sondra Rosendahl, MDH, Licensed Genetic Counselor

Overview of Cytomegalovirus (CMV) was provided by Sondra Rosendahl

- Member of the herpes simplex virus family
- Able to establish lifelong latency after initial infection
- Transmitted by body fluids (urine, saliva, blood, tears, semen, and breastmilk)
- Acquired CMV:
    - Occurs at any age
    - Most people have mild to no symptoms; sometimes causes mononucleosis-like symptoms
    - VERY common (1 in 3 infected by age 5; over half of adults by age 40)
    - Newborns can acquire it from mother's breastmilk
    - Older children (toddlers) often acquire CMV infection in group daycare or from exposure to other children
- Congenital CMV:
    - Occurs when the CMV infection is passed from a pregnant woman to her fetus
    - Could be a primary infection vs reinfection vs reactivation
    - About 1 in 200 infants born with cCMV, but not many people know about it
- Congenital CMV can't be accurately diagnosed in a newborn beyond 14-21 days of age
- Many Faces of cCMV
    - Symptomatic (~10%) – 2 or more features with central nervous system involvement
    - Asymptomatic with hearing loss (~10%)
    - Majority of children do not have hearing loss at birth
    - Asymptomatic (~80%)

Minnesota's Universal Screening Study – presented by Sondra Rosendahl

- Funded through CDC's Emerging Infection Program (EIP) Cooperative Agreement
- Partnership between:
    - CDC – Sheila Dollard, PhD (PI)
    - UMN – Mark R. Schleiss, MD (PI)
    - MDH – Sondra Rosendahl, MS, LGC (PI)
- 6 hospitals, including
    - 3 with NICUs
    - 3 different health systems (Fairview, Allina, and CentraCare)
- Research question - What is the sensitivity of cCMV detection using newborn dried bloodspots compared to saliva?
- 16,096 consented (2/8/2016 – 11/30/2020)

    - ~70% enrolled when approached with option
    - 16,092 newborns screened (excludes QNS, withdrawals, etc):
        - 15,619 (97.1%) from well-baby nursery
        - 473 (2.9%) from NICU
- Diagnostic Outcomes
    - 88 newborns with actionable result
        - 72 confirmed (prevalence of 0.45% or 4.5 per 1000; same rate reported in literature)
        - 14 falsely abnormal
        - 2 declined follow-up
    - Of the 72 confirmed:
        - 12 (17%) symptomatic – mild to severe
        - 3 (4%) hearing loss only – one was a delayed onset
        - 57 (79%) asymptomatic to date
- Study Conclusions
    - Parents and providers seem to be accepting of this testing
    - ~70% of parents approached consented
    - ~98% of families with abnormal results worked with their provider to pursue follow-up
    - Our results shows that the sensitivity of DBS testing for CMV is higher than previously reported (72-75% vs 34%)
    - Perhaps with improved methodologies we could reach 90-95% in the next few years
    - Our study shows the potential of DBS in newborn screening without changing sample type
- 2 forms of infection: acquired vs congenital infection.
    - Acquired CMV – anyone can acquire at any age. Mild to no symptoms. Mono like symptoms or a typical cold. 1 in 3 are infected by CMV by the age of 5. Over 50% of adults have had CMV.
    - Congenital CMV – occurs when CMV is passed from a pregnant mother to their fetus. About 1 in 200 infants are born with cCMV. High incidence of infection but little awareness.
- Complications for testing:
    - testing mothers during pregnancy can be unreliable. There is not a good time to test for it since mothers can get CMV at any time. Bottom line: cCMV cannot accurately be diagnosed beyond 14-21 days of age.
    - Only 10% of infants are symptomatic with 2 or more features with central nervous system involvement. Long term health problems can occur including hearing loss (30 – 50%).
    - Approximately 10% of asymptomatic with hearing loss.
    - Many children are asymptomatic at birth but at risk for long-term health problems. Early detection is key to prevention.
    - Multi-site collaboration study to determine if dried blood spot or saliva sample are better for detection of CMV.
    - PCR testing is used to detect CMV in both dried blood spots and saliva samples.
- The Vivian Act (144.064, section 11)

- Condition Readiness Work Group – included advisors and clinical experts. Plan is to have group meet in Sept/early Oct, Nov, and early Dec. next meeting is October 26th – regularly scheduled meeting. Speakers: Mark Schleiss from the UMN. Sheila Dollard from the CDC and families of children with cCMV. Discussion to follow. January meeting TBD – discussion and vote.
- Potential outcome of vote: package to commissioner prepared, reviewed, and submitted. Commissioner will need to approve the recommendation (no timeline in statute). If approved, MDH begins implementation process. If not approved, documentation provided regarding the denial.

EHDI Advisory Committee Considerations for NBS Advisory Committee Nomination - Input/Discussion - All

Committee members included their thoughts/ideas to the Jam Board: EHDI Advisory Committee - CMV Discussion - Google Jamboard

Question 1: what do we want the NBS Advisory Committee to consider/understand regarding treatment and/or intervention for CMV?
Question 2: How are interventions for CMV unique safe and efficacious, available, and provide significant improvement in quality of life when administered early?
Question 3: What do we (as the EHDI advisory Committee) want the NBS Advisory Committee to consider/understand regarding the elements needed for public health follow-up of the condition?
Question 4: What do we (as the EHDI Advisory Committee) want the NDS Advisory Committee to consider/understand as they identify whether treatment facilities and specialists are available, ready to accept referrals, and willing to manage patients identified through screening?

Decisions Made/Action Items

Send out Jam Board Link – post discussion questions and ideas to board.

Next Meeting
Date: November 17th, 2021
Time: TBD
Location: Virtual
Agenda items: submit proposed agenda items to ehdi@state.mn.us