

Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee May 18, 2022

Minutes prepared by: Jenna Laine

Location: Teams – Virtual Meeting

Attendance

Present: Ingrid Aasan, Renae Allen, Kathy Anderson, Anne Barlow, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Danelle Gournaris, Colleen Ireland, Abby Meyer, Gloria Nathanson, Jessica Novak, Sara Oberg, Elizabeth Pai, Emilee Scheid, Emily Smith-Lundberg, Cat Tamminga, Katie Warne, Terry Wilding,

Absent: Hannah Herd, Tina Huang, Joscelyn Martin, Jay Wyant

Agenda Item Minutes

- **Welcome and Announcements** – Joan Boddicker
- **Logistics** – meeting chat, CART, Zoom and Teams windows
- **Roll call**- committee members listed their names in meeting Chat
- **Approval of Minutes**
 - November 2021 meeting minutes were approved, no corrections or concerns
- **cCMV Background and Implementation** - Sondra Rosendahl & Gina Liverseed, MDH
 - Sondra gave refresher on background of cCMV and Minnesota Universal cCMV Screening Study; Vivian Act, and Advisory Committee process to approve universal screening.
 - A high-level overview of MDH implementation planning status for cCMV including hiring & training more staff, internal/external communication & education; and plan for implementation workgroup to advise MDH. cCMV screening will be done using dried blood spots with recommendation for urine CMV PCR to confirm.
 - Question: How important is the difference between congenital vs. acquired CMV? Is one more severe than the other? Are the long-term effects different?
 - Answer: Acquired, acute, cold like symptoms, it's a virus, over it more quickly. Congenital is a life-long condition, or other interventions may be needed based on other symptoms or congruent diagnoses i.e. hearing loss
 - Continued surveillance of this condition to better understand asymptomatic

- Question: until what age will you follow the kids diagnosed with cCMV?
 - Answer: this is unknown at this time, likely longer than with other blood spot identified conditions, this will be determined later as we move forward with the process
 - Kirsten: MDH will be doing routine checks for changes in hearing status for those who don't present right away with hearing loss, following current best practice, but implementation workgroup will help to finalize timeframes for follow-up
 - Kirsten: Current process, through age 10 audiologists are currently required to report these newly identified hearing losses to MDH
 - There will be short-term and long-term overlap regarding follow-up with cCMV, point of care/short-term follow-up team will be doing more direct follow-up through the case with audiologists, etc. Parent support and other resources will still be concurrently happening through reach out and offering support via the long-term MDH team
- Question: who is on the implementation group and what is the EHDI committee's role/responsibility during this process?
 - Answer: final list of group members for the implementation workgroup are being determined now, and will be expanded further, will include specialists, parents, audiologists, MDH, MDE, Local Public Health, etc.
- Question: Is there a specified follow-up schedule in place for infants that pass the newborn hearing screen, but are CMV positive? How frequently will it be recommended for them to have the repeat testing through infancy and early childhood?
 - Answer: Kirsten: from audiology there are a number of recommendations currently, part of our implementation will be to determine where our process falls within those recommendations. Currently, audiological monitoring is recommended every 6 months. Full diagnostic follow-up needed. New thoughts to monitor every 3 months during the first year. This will be part of the final determinations via the implementation workgroup.
 - Answer: Sondra: goal for implementation workgroup meetings to be completed by end of September, hope to have finalized plan by that time to determine recommendations on follow-up. These plans will be shared with the EHDI committee at a future meeting.
- Question: are you able to collect or do any testing yet before the final follow-up has been determined and/or before the implementation meetings have been completed
 - Answer: the lab needs to develop the test method that's needed to test cCMV with blood spots, once developed, the test needs to be validated (actually showing that cCMV is present) will be using confirmed cases to determine if cCMV results are found
- Question: Who is going to be representing MDE on the CMV implementation meeting?
 - Answer: Cat Tamminga is going to represent MDE, Sue Thomas, pre-school coordinator, kindergarten/first grade age representative hope to have someone in this group included as well
- Question: Are we one of the few states to be doing this?
 - Answer: Yes - we are the first state to implement universal newborn screening for cCMV, using bloodspot
 - Answer: Ontario is doing universal, but we are the first state in the U.S.
 - Answer: There are other states that do 'targeted' screen approach....test only after failed hearing screen. Those states don't use bloodspot though.

- Question: when you did the initial test to determine if babies had cCMV did you use blood spots for this test?
 - Answer: UMN and CDC did the testing, MDH has not done any testing, but we supplied the blood spots for this testing. UMN and CDC has provided us their testing methods, they are not a screening laboratory. We have over 200+ samples coming in each day to MDH lab, and the UMN/CDC labs are not built for high throughput testing like MDH. MDH will use UMN and CDC testing as a starting off point and for reference but their testing does not provide the complete testing package. Test will need to be revised to accommodate larger number of babies being tested

- **cCMV and Early Intervention** - Cat Tamminga, MDE
 - Post-referral/connection to early intervention system, will not look any different with cCMV than any other child referred to part-C. This will, however, likely increase the numbers of babies referred to part-C
 - Some school districts may see an increase
 - Post-referral/connection to school districts, things will look the same
 - cCMV is considered an established condition, and referrals should be made-Help Me Grow or through a local referral directly to school district-this is often seen more in rural communities
 - cCMV is an eligible condition, the family and school district have difference in preferences and services offered, these are determined together with the team and family
 - Education for school districts will be very important. Knowledge/awareness around this condition is lower, schools may not currently know they are serving families that already have this condition
 - Longer term follow-up may be needed, especially with asymptomatic children, ensuring that we don't lose track of these kids, determine through data when these asymptomatic kids are coming into the program later
 - Question: So, all children with cCMV automatically "qualify" for early intervention-even if they are considered to be asymptomatic?
 - Answer: Yes, that's true. Determined once that eligibility happens based on diagnoses. Family may choose to not move forward with services
 - Question: is there any kind of identification for those who didn't have diagnosis via blood spot testing at birth?
 - Answer: newborn screening 24-48 hours of life, every baby will be screened for cCMV except families who refuse testing with blood spot, MN has around 250 refusals per year. Added cCMV to communicable rule-rule that providers, clinicians, labs, required to report to MDH when a child is diagnosed (even later) with one of the conditions on the list. So MDH would be notified if a later cCMV diagnosis.
 - Question: does testing start now with follow-up going forward? Will the older kids i.e. 5 year old be identified now?
 - Answer: no, this will be starting early 2023 and then we will ramp up this process
 - Answer: children with cCMV may already be receiving services
 - Question: what about children with known hearing loss who have cCMV and are school age? Does this change how they would qualify for services?

- Answer: If a child has identified hearing loss, they likely are already receiving services. For part-c, qualifications are broader initially until age 3, criteria changes by degree of hearing loss, for part-B ages 3+ has to have an educational impact. Other complicating factors can impact other services being offered or given to family. Knowing if there is cCMV could be beneficial for older kids identified.
 - Answer: most protocols are child dependent, hard to determine when child is older if the CMV is acquired or congenital, would need to look at each individual child's needs based on the information you have for each child
- CMV Awareness, Education, and Outreach, Gina Liverseed, MDH
 - MDH CMV website in development
 - Education
 - Links to downloadable resources for education and prevention
 - Traditional education/outreach
 - Distribution of print materials, posters, in-person events (community/conferences), swag/handouts, radio ads/other public facing campaigns
 - Educational offerings for MN providers
 - Public and providers-ensuring education gets delivered to all communities to ensure health equity
 - Digital education/outreach including social media
 - Consider our diverse audiences and communities
 - Connections and partnerships
 - Messaging and methods
- **Committee cCMV Feedback/Discussion:**
 - As you think about the addition of cCMV to Minnesota's newborn screening panel, how do you see this impacting your work, particularly as it relates to screening and diagnosis?
 - Education to other providers and families will be most important role
 - Similar role now as a provider, when providing education and information with a cCMV diagnosis
 - I'd love to see Minnesota State Academies included in information sharing and providing parent resources statewide
 - I think for audiology it will increase the number of children we see. With this increase, it will most likely help to create better guidelines for follow-up.
 - As Medical director of audiology, audiology piece will be important, what are the recommendations for screening
 - Pediatric infectious disease and other specialists will provide follow-up for babies with cCMV and they will be followed by their primary care provider/medical home
 - Implementation committee will be helping to shape and update our audiology guidelines
 - As you think about the addition of cCMV to Minnesota's newborn screening panel, how do you see this impacting your work, particularly, as it relates to diagnosis, intervention, and beyond?
 - What is the best way for babies and families to get the support they need through part-c process? Whole family, whole child currently with part-c process. Are there new ways to support these families? Ask-committee, think about creative/new ways to support these families and how babies can get referrals differently to the school districts, etc.

- For additional thoughts & ideas contact Gina Liverseed: Gina.Liverseed@state.mn.us
 - Besides education, what will you need from MDH as cCMV screening and follow-up is implemented?
 - Guidelines of how often audiology will have to report monitoring results for these children.
 - Sharing what you learn with other states and entities, so this possibility ripples out beyond Minnesota
 - When/if they develop hearing loss? Or at each hearing screen?
 - I'd imagine we need to figure out how to support children in rural Minnesota-some families are very far from any resources
- **National EHDI meeting: Improving identification of children at risk for deafblindness in the MDH EHDI system through EHR chart abstraction, Darcia Dierking, AuD, MDH**
 - Project grew out of MDH collaborative plan that the Commission of Deafblind and Hard of Hearing requested data from MDH
 - 78% were known to have been referred to ophthalmology (n=108)
 - 56% of the total 108 are known to have been evaluated by ophthalmology
 - Among children with risk factors for deafblindness, 70% were evaluated by ophthalmology.
 - This poster won the best poster at the EHDI national conference!!
 - Darcia posed several questions to the committee about next steps.
 - Comment: great that a lot of team members were able to attend the EHDI national conference, several people took to heart to remember to keep kids as kids, encourage play, and remember the fun things and experiment, along with all other great data and information provided
 - Comment: family interactions and focus on kids being kids was good. Late identified hearing loss sessions, continued need for monitoring children's hearing and how to support them if they are identified later
- **Minnesota Department of Education update, Mary Cashman-Bakken**
 - Collaborative conference will be in November
- **Federal reporting for part-c, Cat Tamminga**
 - Part-c is required to provide reporting to federal oversight groups
- **Minnesota Low Incidence Project, Kathy Anderson**
 - mnlowincidenceprojects.org-website now live
 - Allowing access to all the same resources
 - Workgroup of educational audiologists and education providers
 - MN Early Hearing Detection and Intervention (EHDI) interagency initiatives: information resources for clinical audiologists on referrals and early intervention supports for young children with hearing differences, 2022

Next Meeting

Date: August 17, 2022

Time: 1:00 – 4:00 pm

Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104

Agenda items: submit proposed agenda items to ehdi@state.mn.us